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DOES CULTURE MATTER?
EXPLORING THE RELATIONSHIPS AMONG PARENTING A CHILD WITH
DISABILITIES, CULTURAL IDENTIFICATION, AND STRESS IN A GROUP OF
EUROPEAN AMERICAN AND IMMIGRANT LATINO FAMILIES

By

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B.Sc. Universidad Peruana Cayetano Heredia, 1994
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A Dissertation
Submitted to the Faculty of the
Graduate School of the University of Louisville
In Partial Fulfillment of the Requirements
For the Degree of

Doctor of Philosophy

College of Education and Human Development
University of Louisville
Louisville, Kentucky

May 2006

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A Dissertation Approved on

April 24, 2006

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DEDICATION

I dedicate this dissertation to my daughter Misqa and my husband Yuri.
Your unconditional love and countless easy smiles sustain the most peaceful and
solid home I could have ever wished for.

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I would like to thank the members of my dissertation committee, Dr. Thomas Simmons, Dr. Debra Bauder, Dr. Denzil Edge, Dr. Pedro Portes, and Dr. Bibhuti Sar for their support in the process of completing this project. I would also like to thank Dr. Karen Nakasato Takahashi, Lolita Sousa Cacho and Dr. Maria Vasquez-Colina for their assistance in translating the Questionnaire on Resources and Stress.

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I am eternally thankful to my parents, Lola and Jorge for the life sculptures that taught me about beauty and eternally grateful to my brother Eduardo for the music that he is constantly playing in my heart.

ABSTRACT

DOES CULTURE MATTER? EXPLORING THE RELATIONSHIPS AMONG PARENTING A CHILD WITH DISABILITIES, CULTURAL IDENTIFICATION, AND STRESS IN A GROUP OF EUROPEAN AMERICAN AND IMMIGRANT LATINO FAMILIES

Ximena P Suarez-Sousa
April 24, 2006

The purpose of this correlational exploratory study was to delve into the experience of raising a child with disabilities by investigating the parents' level of stress and the role played by culture, acculturation, and various demographic variables suggested by the literature to influence stress were included. A purposive sample composed of 38 primarily undocumented immigrant Latino parents and 32 European American parents of children with disabilities was recruited from community agencies in a Midwest state. The most frequent disabilities were orthopedic impairments, pervasive developmental disorders, and mental retardation.

Data were collected with the Parent Survey, comprised of the Questionnaire on Resources and Stress-QRS, the Orthogonal Cultural Identification Scale-OCIS and a section on demographic information. A Spanish version of the Parent Survey was produced in order to collect data from monolingual Latinos. Preliminary validation of the QRS was conducted.

Results indicated that there was no difference in the level of stress between immigrant Latino and European American parents, both cultural groups

showed similar stress profiles. Multiple regression indicated that the best predictor of stress among Latinos were the appraisal of child's motor development, level of cultural identification with the host culture (Level 1), and level of cultural identification with the Latino culture. Among European Americans, the best predictors of stress were the appraisal of child's cognitive development and appraisal of life satisfaction. Cross culturally, although mothers reported higher levels of personal burden, levels of stress between mothers and fathers were similar.

Practitioners should take into consideration, when collaborating with culturally diverse families, the process of acculturation to the host society which makes the experience of raising a child with disabilities more complex. Further implications and recommendations for research and practice were discussed.

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*"Men are disturbed not by things which happen,
but by the opinions about the things"*
Epictetus, Enchiridion

CHAPTER I

INTRODUCTION

Parenthood may be counted as one of the most challenging life experiences, one that can impose tremendous demand on the individual (Pancer, Pratt, Hunsberger, & Gallant, 2000). The experience of raising a child is not solely influenced by demographic factors such as the gender of the parent, his educational level, or marital status. Raising a child is also influenced by the parent's socioeconomic, political, and cultural environments (Bronfenbrenner, 1979; Belsky, 1984; Osofsky & Thompson, 2000) and by phenomenological factors such as the meanings (i.e., interpretations) the individual renders to concepts that are intimately related to parenthood (Lazarus & Folkman, 1984); for instance, being a single parent, being the parent of a child with disabilities, or being an undocumented immigrant parent. The various meanings construed by the individual will have a distinctive influence on the parenting experience and will also have the potential for setting off an array of psychological and behavioral outcomes (i.e., feelings of burden) that have been commonly identified as manifestations of stress. This study aims at delving deeply into the experience of parenting a child with disabilities by culturally diverse individuals.

Research has demonstrated that qualitative differences exist between parenting a child with a typical development and parenting a child with disabilities (Atkin & Ahmad, 2000; Esdaile & Greenwood, 2003). Studies conducted across the globe have consistently shown that parents of children with disabilities experience higher levels of stress than parents of children with a typical development (Koegel, Schreibmann, Loos, Dirlich-Wilhelm, Dunlap, Robins, & Plienis, 1992; Abelson, 1999; Baxter, Cummins, & Yioltis, 2000; Bhagwanji & Suarez-Sousa, 2002). Individuals raising children with disabilities have been described as being concerned about a vast array of issues related to the child's wellbeing. For example, the child's behavior, the child's ability for reaching an independent life, the extended family's reactions to the child's disability, the community's response to the child, the associated economic expenses, the burden placed on siblings, among others (Holroyd, 1987; Suarez-Sousa, 1994; Abelson, 1999).

The body of empirical research depicts the experience of parenting a child with disabilities as impacting on parents' general sense of socioemotional and economic well-being and as also affecting the parenting skills (Lazarus & Folkman, 1984, Cummins & Baxter, 1997). Ineffective parenting can negatively impact on the developmental outcomes of a child with disabilities (Magill-Evans & Harrison, 2001), triggering in this way a detrimental cycle that could inhibit the child's potential for development. Current evidence-based knowledge has clearly established associations between the birth of a child with disabilities and various psychosocial and behavioral outcomes that have become identified by the

general term of stress and this study aimed at further exploring this association.

However, the present study approached stress assuming that it is not a standard outcome among parents of children with disabilities. Although not numerous, some studies have examined the positive impact that a child with disabilities has on her parents as well as her family (Mullins as cited in Hastings & Taunt, 2002; Noh, Dumas, Wolf & Fisman, 1989; Stainton & Besser, 1998). Some studies have examined the role played by various coping factors in buffering stress, amongst which the parent's culture is of great interest for this study. Culture may facilitate a coping response to the experience of parenting a child with disabilities because it determines the way by which the world is understood and consequently the behaviors and meanings that are assigned to life experiences (Joe, 1992). The need for knowing about the role played by the parents' culture is critical in that service providers can err when standardized intervention programs are implemented in their work with diverse populations, missing to look at parents' mediating and moderating factors that in the long run can have great influence in the rate of efficacy of intervention programs (Wolery & Bailey, 2002).

Considering that the demographic profile of the United States is composed of approximately 70 million people who describe their culture as being different from mainstream American culture, it is relevant to examine the role this variable plays in the experience of stress among families raising a child with disabilities. This information could guide service providers in the development of effective and culturally responsive intervention programs; particularly, when working with

Latinos who make up the largest minority group in the US (U.S. Census Briefs and Special Reports, 2000).

This exploratory study was specifically interested in examining the experience of immigrant Latino parents of children with disabilities, primarily undocumented, and comparing it with that of parents from mainstream America. Since Latinos have been found to have the highest rate of non-proficiency in the English language than any other non-English speaking immigrant groups in the US (U.S. Census Briefs and Special Reports, 2000), all data from Latino participants were collected in their native language. For this purpose, this study translated into Spanish the Questionnaire on Resources and Stress – QRS, and conducted required statistical procedures for determining its preliminary coefficients of validity and reliability. The QRS is an instrument that has been broadly utilized for the purpose of measuring stress among parents of children with various types of disabilities.

The knowledge resultant from this study could be used as a tool to better understand the role played by culture in the individual's experience of raising a child with disabilities. Several demographic and cultural variables were analyzed within a exploratory correlational research design. Emphasis on exploring the role of acculturation, a psychosocial phenomenon describing the process by which an immigrant adapts to a host culture, is of utmost importance when providing services to recently arrived immigrants such it was the case of participants in this study.

Theoretical Framework

Three theories were selected to provide a theoretical framework for this study. The first one, Lazarus and Folkman's Transactional Model of Stress and Coping (1984), describes the ways by which the individual's idiosyncratic appraisal of life events becomes the crucial predictor in the experience of stress. Lazarus and Folkman stated that the appraisal process is a very intimate and subjective psychological phenomenon; and thus, a similar life event faced by two different people possessing similar social, emotional, and economic resources may be appraised as challenging to one (i.e., disturbing) and as a threat to the other (i.e., damaging). Consequently, in the range of variability in the appraisal process lays the explanation for the variability in the quality of behavioral and psychological outcomes observed among individuals who are facing similar life events. This study assumed that the interpretation (i.e., appraisal) given to a life event, such as the birth of a child with disabilities, is a phenomenological process that is highly influenced by the individual's culture.

The second, Bronfenbrenner's Ecological Model of Human Development (1979), provides a reference for understanding the impact that the individual's ecological environment has on human experience and human development throughout all stages of life, including the stage of parenting a child. The ecological environment that Bronfenbrenner describes is composed not only by the individual's family and immediate community, but it is inclusive of larger social systems such as the society at large, the nation, and culture. Bronfenbrenner's model will be utilized to understand the immigrants'

experience, in which the influences exerted by the societies of origin (i.e., native macrosystem) –from which immigrant Latinos are physically disconnected, but psychological connected—and the host society (i.e., host macrosystem) are intertwined. These two societies constitute two very different ecological environments, actively engaging and acting upon the individual's psyche and behavior with similar relevance.

Finally, Oetting and Beauvais' (1990) Orthogonal Cultural Identification Theory takes a direct look at the process of cultural identification. This theory provides a basis for understanding cultural identification, with own culture and with the host culture, as an ongoing social learning process. Immigrants do not abandon their native cultural practices, values, and beliefs as means for adapting and identifying to the host society. The orthogonal model states that an individual, given its level of exposure to any culture, has the potential for identifying with one, two, or many more cultures simultaneously; or identify with none of them. This model provided a basis for better examining the acculturation process of immigrant Latino parents of children with disabilities recently arrived to the United States.

Statement of the Problem

Many events defined as stressful that people encounter throughout their lives are relatively ephemeral. That is the case, for example, of the stress produced by an examination which will be soon gone after the last question is answered, or when test results are received (Clovis, 1999). The stress of losing a job will vanish when a new one is landed (Crowley, Hayslip Jr., & Hobdy,

2003), and the stress associated with getting into college goes away as soon as admission is secured (Fallows, Bakke, Ganeshanathan, & Johnson, 2003). Nevertheless, not all life events that are appraised by individuals as stressful are short living. One example is the birth of a child with disabilities, a life event that has been described by a large percentage of the literature as being a life-lasting source of stress (Harrison, Richman, & Vittimberga, 2000; Lemanek, Jones, & Lieberman, 2000; Peebles-Kleiger, 2000).

According to Lamberti and Detmer (as cited in Kroth and Edge, 1997) parents of children with disabilities often grieve for themselves, particularly for what they considered has been *lost*; that is, the child they dreamed about throughout the gestational period. The experience of disclosure of disability triggers a double appraisal process as means for the individual to estimate the severity of the event (Lazarus and Folkman, 1984). The primary appraisal defines the event in the context of previous experiences, either personal or vicarious, and determines whether it is a familiar or an unfamiliar event. The secondary appraisal looks at the types of resources the individual possesses at that time and that are thought to be instrumental in facing the event satisfactorily (e.g., time, emotional support, money, knowledge, motivation, social skills).

The disclosure of disabilities would be appraised as a stressful life event if the individual concurs that he is lacking the necessary psychological, social, or economic resources to face it in a satisfactory manner. Research has found that women most frequently than men concur they lack the necessary resources; consequently, mothers of children with disabilities are prone to experience higher

levels of stress than fathers (Pelchat, Ricard, Bouchard, Perreault, Saucier, Berthiaume, & Bisson, 1999; Hastings, Thomas, & Delwiche, 2002). Other studies have further examined a myriad of factors impacting on parents' appraisal process. For instance, factors such as the child's low level of independent functioning or high level of behavioral problems were found to quickly deplete parents' appraised available resources (Gowen, Johnson-Martin, Goldman, & Appelbaum, 1989; Baldwin, Brown, & Milan, 1995; Hastings, 2000; Jackson, 2000). Single parenthood and lower income levels have also been found to have a negative impact on the individual's ability to cope with stress (Baldwin, et al., 1995; Olsson & Hwang, 2001). On the contrary, social support, religion, spirituality, the accessibility to respite care services, and higher educational levels have been all shown to accrue to the pile of available resources used in successfully coping with stress (Hobfoll & Spielberg, 1992; McAdoo, 1995; Cummins & Baxter, 1997; Little, 2002).

Although the literature on stress and families of children with disabilities is quite copious and has enriched the practical and theoretical knowledge of practitioners working in the early intervention and early childhood special education areas, it has been limited to the extent that knowledge from this scholar production is not generalizable to the culturally diverse populations practitioners may encounter on a daily basis nowadays in the United States. A great majority of the literature on stress and disabilities has been conducted with predominantly middle class European American mothers with a recurrent exclusion of fathers. To great extent, this body of literature has been weak in

incorporating groups that are diverse from mainstream America. Finally, there have been almost no attempts at reaching populations living in the United States whose native language is not, and who do not speak, English.

These deficiencies are striking considering today's demographic make-up of the US; particularly when it comes to the Latino population, which currently constitutes the largest minority (U.S. Census Briefs and Special Reports, 2000). Padilla and Medina (as cited in Carrol, 2001) have highlighted that Spanish speakers maintain the use of their language at levels such that "an adequate assessment of family relationships can occur only when people are assessed within the context of their cultural environment, which includes an appropriate match of language" (p.212). Research on parents of children with disabilities needs to be inclusive of members of diverse cultural groups, particularly recent immigrants, not only for the benefit of practitioners in the US but for those in other countries with a high incidence of immigration (e.g., Western Europe). Considering that culture is powerful in influencing and shaping the world view of an individual (Patterson & Leonard, 1994), it could be said again that the experience of stress, which is greatly shaped by the individual's own appraisal of the situation, would be likewise influenced by the individual's culture. Any findings in this venue would support the establishment of alternative intervention approaches to culturally diverse populations raising children with disabilities and may initiate the exploration of strategies that could be cross-culturally applied. This cultural exploration is one of the gaps in the current literature that this study attempted to fill.

Although the concept of culture has a rich variety of definitions given by various theoretical frameworks, in general, culture is considered a social construct that serves the purpose of identifying “insiders as well as outsiders mutually acknowledging group differences in cultural beliefs and practices” (Sanders, 2002, p.327). To Garcia-Coll and Magnuson (2000), culture is a complex construct which is often entwined with the concepts of ethnicity and race. Ethnicity being understood as the subjective affiliation to a group of individuals sharing nationality, language or culture; while race is primarily defined in terms of phenotypical characteristics such as hair type or skin color. Lynch and Hanson (1999) have defined culture as “the framework that guides and bounds life practices” (p.4) among which parenthood is not an exception.

The beliefs, ideologies, norms, and values of a given cultural system seem to have an impact on how culturally diverse individuals appraise life events and cope with them in culturally-influenced different ways. Joe (1982) described how among Navajo families of children with disabilities stress was an almost nonexistent experience due to a social structure that creates a web of available *surrogate* mothers for each child. Latinos for example, a culturally diverse group within itself, possess certain psychosocial characteristics that are extremely relevant for the purpose of conceptualizing and dealing with *disabilities*: Their strong family ties, the importance bestowed to interpersonal relationships, their relaxed attitude towards independence and individuation of young children, their catholic religiosity, and their nurturance, permissiveness, and indulgence with young children (Lynch and Hanson, 1998). These culture-specific characteristics

may help Latinos to better cope with stress. It is important to look at cultural differences among individuals as they have been found to produce differentiated interpretations of disability (Saetermore, Scattone, & Kim, 2001) and consequently, differentiated psychological and behavioral outcomes when giving birth to a child diagnosed with one.

When studies look at diverse migrant groups living in a host culture, such as it is the case of millions of individuals around the world and in particular the case of Latino immigrants living in the US, the variable culture needs to incorporate the process by which immigrants adapt to the new sociocultural environment. This acculturation process, defined as the magnitude by which an individual maintains a culture of origin versus adapts to the new society's culture (Garcia-Coll and Magnuson, 2000), encompasses both, the incorporation of the host culture's values and behaviors as well as the upholding of the native culture's beliefs (Garcia-Coll, Meyer, & Brillon, 1995).

Jean Phinney (2000) warned that researchers interested in studying factors related to culture would "face the challenge of conceptualizing culture in a way that can be studied empirically" (p.43). Oetting and Beauvais (1990) have indirectly responded to this need by developing the Orthogonal Cultural Identification Scale (OCIS) which was utilized in this study. This is an instrument that measures cultural identification, with the possibility of the respondent identifying with more than one culture at a given time, or with none at all. This instrument gave this study the possibility of exploring the process by which an immigrant's culture may evolve over time by comparing individuals who have

been residing in the host culture for different periods of time, as well as determining the quantitative incorporation of cultural elements of the host culture into the immigrant's psyche and behavior. All these will make possible the examination of the experience of stress among Latino immigrant parents of children with disabilities.

Purpose of the Study

The main purpose of this exploratory correlational study was to investigate the association between *culture* and *stress* in a population of primarily undocumented immigrant Latino and European American parents of children with disabilities. Additionally, this study aimed at examining the role played by two groups of predictor variables, a) demographic predictor variables (i.e., age, gender, marital status, level of education, family income, occupation, number of working hours, appraisal of life satisfaction, health status, age and gender of the child, diagnosis, appraisal of child development) and b) cultural predictor variables (i.e., cultural identification with own culture, cultural identification with host culture, years living in host country, country of origin), in the experience of stress. This study also aimed at translating and conducting preliminary validation of a Spanish version of the short Questionnaire on Resources and Stress (Holroyd, 1987) with the purpose of reaching Spanish-speaker parents not proficient in English. A background, more general, purpose was to identify potential universalities in the experience of stress as well as identifying the areas of variability between these two cultural groups.

Research Questions and Hypothesis

Two major specific research questions and one hypothesis guided this study:

Research question # 1: What are the preliminary coefficients of reliability and validity of the Spanish Questionnaire on Resources and Stress – short version?

Research question # 2: What relationships exist among stress, cultural variables, and demographic variables in a sample of immigrant Latino and European American parents of young children with disabilities?

Non-directional null hypothesis: H_0 : There is no statistically significant difference in the levels of stress between Latino and European American parents of children with disabilities ($\mu_L = \mu_{EA}$).

Non-directional research hypothesis: H_1 : There is a statistically significant difference in the levels of stress between Latino and European American parents of children with disabilities ($\mu_L \neq \mu_{EA}$).

Research has indicated that parenting a child with disabilities is, in the great majority of cases studied, a very stressful experience (Gallagher, Beckman, & Cross, 1983; Factor, Perry, & Freeman, 1990; Esdaile & Greenwood, 2003) and, although not free from some conflicting results, various demographic variables (e.g., age of parent) have been found to be associated with higher levels of stress (Macias, Clifford, Saylor, & Kreh, 2001). Additionally, culture has been acknowledged to generate variations in how individuals define the concept of disability (Kobasa, Maddi, & Kahn, 1982; Groce as cited in Lamorey, 2002), and so does the potential for an increased variance of the stress experience

across cultures. In order to create bridges that would access non English-speakers, personal interviews and psychometric instruments should be made available in their native language (Padilla & Medina, as cited in Carrol, 2001). The lack of research-based knowledge about the experience of raising a child with disabilities by culturally diverse groups as well as the lack of psychometric instruments that would create research accessibility to these populations, were issues that the present study tried to address.

In this study all data were collected with the Parent Survey, which was comprised of the following instruments: a) The short version of the Questionnaire on Resources and Stress (Holroyd, 1987), b) The Orthogonal Cultural Identification Scale (Oetting & Beauvais, 1990), and c) Twenty seven questions for the retrieval of demographic and culture-related information. Descriptive statistics (i.e., means, standard deviations, ranges, frequencies) and inferential statistics (i.e., T-Test, Pearson product-moment correlation, Spearman Rho correlation, first order partial correlation, hierarchical multiple regression) were utilized to analyze the quantitative data collected. Content analysis was utilized in the examination of qualitative data.

Significance of the Study

The present study will produce new knowledge that will be both practically and theoretically relevant. In terms of its practical application, information from this study can be directly utilized in modifying and improving the quality of services rendered to Latino and European Americans families as well as supporting the implementation of research-based intervention programs. Thus,

families of children with disabilities will indirectly benefit as well from this study. For example, the study can shed light into some of the general assumptions made about the Latino culture one of which being that family units tend to live in close physical proximity and from which social and emotional support is received; this may not necessarily be the case among relatively recent arrived immigrants (i.e., living in the US for less than a decade). Theoretically, results from this study will contribute to the general existing knowledge on stress, corroborate or challenge the models used as framework in this study, particularly filling the existing gap on cross-cultural research on this topic. For example, developing an exploratory multiple regression model will facilitate the identification of predictor variables to a successful coping that are culture-specific and that can be utilized by service providers as well as researchers in the field. Similarly, this study can also help in the identification of factors affecting the efficacy of intervention programs, thus opening a venue for further research. This study will produce the following additional benefits:

1. To translate and, thus, make accessible a valid Spanish version of an instrument utile for exploring stress among Latino families. This is of great relevance considering the demographic composition of the special education population in the US and the need for culturally appropriate evaluations (Wolery & Baley, 2000). The information obtained from this empirical study could benefit culturally diverse families of young children with disabilities; specifically, Spanish speaking parents who are not

proficient in English and for whom there is a dearth of instruments available in their native language (Solis & Abidin, 1991).

2. To contribute to the field of special education and its scarce cross-cultural literature on stress by supplying information about the role that culture plays in the general experience of parenting a child with disabilities; particularly when it pertains to recent immigrant families dealing with issues of acculturation.
3. To further explore the experience of fathers, who have recurrently been omitted from the literature and examine how their experience compare with that of mothers regarding their areas of strength and areas that may need gender-specific intervention.
4. To support theories and models explaining the influence of culture in human behavior and emotion, particularly those that pertain to families of children with disabilities.
5. To identify models and practices for supporting families living in high-risk conditions, such as it is the case of non-English speaking, undocumented non-majority culturally diverse groups.

Delimitations and Limitations of the Study

This study attempted at exploring the experience of stress among culturally diverse populations. When it comes to the Latino population, the study specifically targeted permanent immigrants regardless of the immigration status (e.g., undocumented), with the exclusion of seasonal workers and refugees (e.g., political persecution). Parents of adults with disabilities were not included in this

study, nor were grandparents or foster parents. The primary targets were the biological or adoptive parents of children with disabilities.

The major limitation of this study can be found on its sampling process and thus, in the capability to generalize its results to a larger population. In the planning stages previous to the beginning of the study it was assumed, and confirmation of participation was informally obtained, that a state-based agency providing services to families of children with disabilities would facilitate access to the population. In the end this was not possible and a purposive sampling was utilized; recruitment of participants was conducted through various local agencies and from word of mouth. The primary explanation for the lack of support seems to be found on the protection given by state-based agencies to their Latino clients who, in the majority of cases within the geographical area represented by this study, are undocumented immigrants. Additionally, immigrants themselves are not necessarily willing to become in contact with individuals conducting studies and retrieving information whose purpose may not be amply understood by them, which was particularly the case of participant Latino fathers. Nevertheless, word of mouth (i.e., informal referral) tremendously facilitated the recruiting process of Latino participants in general. Other, less critical limitations will be further described in chapter 5.

Definitions

In the context of this study, the following definitions were utilized:

Appraisal of Child Development: Total score obtained on items 83 through 87 on

the Parent Survey. This is a subjective evaluation of child's development. This does not necessarily correspond to results from formal developmental assessment; it only reflects what the parent thinks about child's progress on each developmental domain (i.e., motor, communication, cognitive, social/emotional, and adaptive).

Country of Origin: Nation where the respondent was born and spent most of their life prior to moving to the United States.

Cultural Identification with Host Culture: Total score obtained on items 88 through 93 on the Parent Survey. This represents the "strength of a person's links to [the host culture]" (Oetting, Swain, & Chiarella, 1998).

Cultural Identification with Own Culture: Total score obtained on items 88 through 93 on the Parent Survey. This represents the "strength of a person's links to [own culture]" (Oetting, Swain, & Chiarella, 1998).

Disability: The "interruption, delay, or restriction of the sequence and rate of normal growth, development, and maturation due to congenital abnormality, trauma, deprivation, or disease" (Thomas, 1993).
Either one of the 13 categories described by the federal government, specifically by the Individuals with Disabilities Education Act as qualifying the child for receiving special education services. These are: Autism, deaf-blindness, deafness, emotional or behavioral disturbance, hearing impairment, mental retardation, severe/multiple disabilities, orthopedic impairments, other health

impairments, specific learning disability, speech and language impairments, traumatic brain injury, and visual impairment-including blindness

European American: A person who culturally/ethnically identifies himself or herself as such in the Parent Survey. A person of European ancestry who is a US national.

Family Stress: The composite score obtained by adding scores from scales III, V, and IX on the Questionnaire on Resources and Stress – QRS. It reflects the respondent's preoccupation about the quality of family relationships, the financial status, and opportunities for growth.

Health Status: Score obtained on item 79 of the Parent Survey and qualitative description of recurrent illnesses.

Hispanic/Latino: A person who culturally/ethnically identifies himself or herself as such in the Parent Survey. A person born and raised in a Latin American country (e.g., Argentina, Honduras, Ecuador, Mexico) or raised by Hispanic parents in any other nation outside Latin America.

Index Case Stress: The composite score obtained by adding scores from scales I, II, and VIII on the Questionnaire on Resources and Stress – QRS. It reflects the respondent's preoccupation about the child's condition and capability for independent living.

Life Satisfaction: Score obtained on item 78 of the Parent Survey. It provides a

subjective evaluation made by the respondent's regarding his quality of life.

Number of Years Living in the US: Time elapsed since the entrance into the US territory.

Stress: The total score obtained on the Questionnaire on Resources and Stress (Holroyd, 1987). This represents a psychological state reflecting the "particular relationship between the person and the environment that is appraised by the person as taxing or exceeding his or her resources and endangering his or her well-being" (Lazarus & Folkman, 1984, p.19).

Personal Stress: The composite score obtained by adding scores from scales IV, VI, VII, X, and XI on the Questionnaire on Resources and Stress – QRS. It reflects the respondent's preoccupation due to the degree and amount of responsibilities assumed in the care of the child and the implications these may have to personal growth and development.

Conclusion

This chapter has presented a general summary of the study. It provided brief descriptions of the theoretical framework that guided this project, the core problem under examination, the research questions and hypothesis, the purpose and significance of the study as well as its delimitations and limitations. It ends with the definition of terms that will be utilized throughout this study.

Unarguably, the knowledge produced by this study will contribute in the development of intervention programs for children with disabilities and their families. In nations such as the United States of America in where the rate of immigration is high (Papademetrious, 2002), the need for research inclusive of culturally diverse groups, particularly of recent immigrant individuals dealing with issues related to acculturation (Michelson, 2003), becomes a priority. Knowledge from this study will provide additional tools for the development of culturally responsive intervention programs for immigrant Latino families of children with disabilities.

CHAPTER II

LITERATURE REVIEW

Introduction

The preceding chapter provided an overview on stress, disabilities, and culture and presented a general context to better understand the significance of conducting a more in-depth examination of the association among variables. The purpose of this study was to gain insightful knowledge about the experience of parenting a child with disabilities among culturally diverse populations. This chapter has as its main objectives to present more in-depth research-based information on stress and culture as well as to examine an array of predictor variables that have been found to be associated with stress. This chapter also provides a foundation for the formulation of the research questions and main research hypothesis. With that purpose, the present chapter has been divided in two parts.

Part one presents an in depth review of the models that provide the theoretical framework for this study. These are: a) Lazarus and Folkman's Transactional Model of Stress (1984), b) Bronfenbrenner's Ecological Model of Human Development (1979), and c) Oetting and Beauvais's Orthogonal Cultural Identification Theory (1990). These theoretical models were selected for the

reason that they place a great emphasis on the role that socioeconomic and cultural contexts play on human behavior and experience. In this way, it will help the reader to better understand the relationship that exists among stress, disabilities, and culture. Part one will also present the current research supporting the propositions formulated by these theories, encompassing the focal points of the study which are stress, disabilities, and culture. In conjunction, parts one and two will provide a descriptive context in which to understand the impact that having a child with disabilities may have on primarily undocumented Spanish monolingual Latino immigrants and on European American parents.

Part two provides information about best practices for the translation of psychometric instruments that have guided the translation process of the Questionnaire on Resources and Stress – QRS, short version (Holroyd, 1987). For the purpose of collecting data on stress with the Spanish speaking population, this study conducted preliminary validation of a Spanish version of this instrument. Finally, conclusions from this chapter will be presented.

Stress and Disabilities

Theoretical Framework

In the 1950s and 60s theoretical propositions on parents and disabilities encompassed narrow unidirectional relationships, most of which were substantiated on the practitioners' personal experiences rather than on extensive externally and internally valid research. Some of these theories explained the causal role that parents played in the etiology of their children's disabilities (i.e., "blaming the parent" theories). For example, Bruno Bettelheim (1967) took from

Leo Kanner the *refrigerator mothers* hypothesis (i.e., detached, aloof, cool mothers) for his psychogenic theory on autism explaining how mothers produced such detrimental under-stimulating family environments that resulted in their children's self-protective response mechanism for surviving under those living conditions devoid of parental warmth and attachment. It is of no surprise that these theories induced acrid, guilty sentiments on parents—particularly mothers. On the other hand, models of parental grief placed emphasis on the negative impact that the child with disabilities had on his parents. For instance, Solnit and Stark (1961) as well as Olshansky (1962) described, respectively, the *chronicity of mourning* and the *chronic sorrow* phenomena that were said to be experienced by all parents of children with disabilities. These models of mourning adduced that parents would never recover from losing their ideal (i.e., dreamed) child and consequently parents were at risk for staying on a pervasive lifelong state of grief.

In the past decades, new systemic models have been developed; these models looked into a compound of directional relationships among parents, children, the family context as a whole, the community, the larger society and its socioeconomic characteristics, and the macro culture in where individuals live. These models take many variables into consideration for better understanding human development, as well as psychological, and behavioral outcomes. The parent-child relationship and the parent's and child's process of development are now seen within a more complex web of interconnected factors. Three of these

models have been selected with the purpose of constituting the theoretical framework for this study.

The Transactional Model of Stress and Coping: Richard Lazarus and Susan Folkman (1984).

The model of Lazarus and Folkman provides the tools for better understanding the construct of stress. This model encompasses two overlapping dimensions: a) the environmental (i.e., the positivist realm) in where most potential stressors are found, and b) the personal (i.e., the phenomenological realm) which is characterized by the individual's appraisal of the environment. Lazarus and Folkman (1984) provided the following definition, "psychological stress is a particular relationship between the person and the environment that is appraised by the person as taxing or exceeding his or her resources and endangering his or her well-being" (p.19). In general terms, stress is defined as a psychological, bi-directional phenomenon that occurs between the person and his or her environment; which is cognitively mediated and can be experienced at different intensities, (i.e., from innocuous to life threatening), mostly as something that comes and goes and which has as its principal characteristic the lack of equilibrium between the individual's abilities to face comfortably the environmental demands and the level of such demands (Smith, Sarason, & Sarason, 1984; Kellogg & Pisacreta, 1993; Ishlander & Greenblat, 1994). Although Lazarus and Folkman do not specifically talk about cultural differences among individuals, they do highlight the existence of "great variations in human response to so-called stressors" (1984, p.19) and that these variations are due to

the individual's personal experiences, values, and beliefs; all of which are highly influenced by culture. As they stated,

“In general, individuals give to any event a threat value that will set the standard for reacting. No longer can we pretend that there is an objective way to define stress at the level of environmental conditions without reference to the characteristics of the person” (p.19).

The authors' emphasis on the phenomenological aspect of the experience of stress leaves no room for the assumption that a similar event, such as the experience of having a child with disabilities, would be experienced by every parent in a similar fashion. The individual's *cosmovision* (a word that the author is borrowing from the Spanish language); that is, the peculiar ways through which each person perceives and understands the world and that is strongly influenced by the culture this person belongs to, will produce a myriad of possible responses to a similar life event by various persons and also varied responses by the same person if experienced at different facets of his life. To Lazarus and Folkman (1984), “people and groups differ in their sensitivity and vulnerability to certain types of events, as well as in their interpretations and reactions” (p.22); in this regard, they suggest that research should aim at understanding “human variation under comparable external conditions” (p.23). The transactional model of stress describes the phenomenological aspect that mediates the person-environment relationship as occurring at two different levels: a) cognitive appraisal and b) coping (See Figure 2.1). In conjunction these two levels will affect the individual's adaptational outcomes to the stressful event. Adaptational outcomes

for Lazarus and Folkman are, “functioning in work and social living, morale and life satisfaction, and somatic health” (p.181). The following section will take an in-depth look at the appraisal and coping processes.

a) *Cognitive appraisal*: Cognitive appraisal is defined as, “an evaluative process that determines why and to what extent a particular transaction or series of transactions between the person and the environment is stressful” (Lazarus & Folkman, 1984, p.19). This process mediates the individual’s reactions and it is considered by this model to be crucial for adequate psychological understanding and estimation of how much the event has the potential for impairing the individual’s well-being. Importantly, cognitive appraisal is an intimate, subjective process which does not necessarily maintain an objective relationship with the reality of the environment. Cognitive appraisal is composed of two parallel evaluative processes: a) Primary appraisal and b) Secondary appraisal, and Lazarus and Folkman have emphasized the fact that neither one precedes the other.

During primary appraisal the question that is asked by the individual is, because of this event “Am I in trouble or being benefited now or in the future, and in what way?”

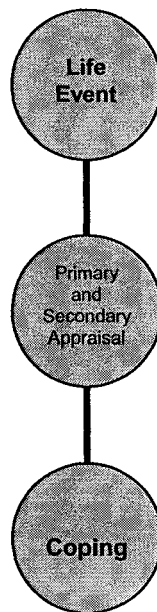


Figure 2.1 – Transactional Model of Stress and Coping

There are three different forms of primary appraisal:

PA1. Irrelevant: When the encounter with the environment does not threaten the individual's wellbeing. The individual will not lose or gain anything from this transaction with the environment.

PA2. Benign/Positive: When the encounter with the environment preserves or enhances the individual's wellbeing or augurs such an enhancement.

PA3. Stressful: When the encounter with the environment harms (i.e., damage has occurred), threatens (i.e., damage has not yet occurred, but coping emotions are negative: fear, anxiety, anger), or challenges (i.e., damage has not yet occurred, but coping emotions are positive: eagerness, excitement) the

individual's wellbeing. Those individuals who feel challenged rather than threatened are the ones that will eventually cope and adapt better to the environmental demands. These forms of primary appraisal are further illustrated in Figure 2.2.

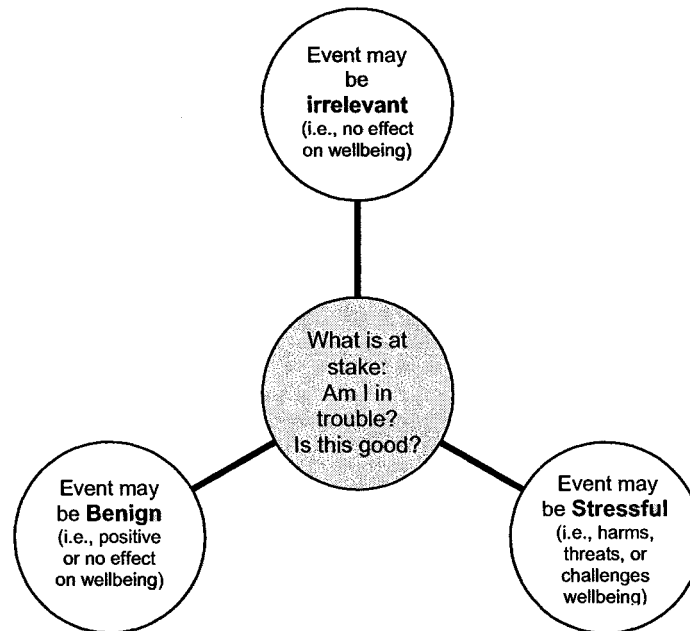


Figure 2.2 – Cognitive Appraisal: Primary Appraisal

During secondary appraisal the question that is asked by the individual is, "What, if anything, can be done about [this event]?" This evaluative process makes the individual search for things that should or could be done as a response to the environmental demands as well as identifying the coping options available to her. In explaining the role played by appraisal in the resultant experience of stress, these authors stated, "secondary appraisals of coping

options and primary appraisals of what is at stake interact with each other in shaping the degree of stress and the strength and quality (or content) of the emotional reaction” (p.35). Some of these reactions can be changed through a process of *reappraisal*, or a changed primary appraisal, that occurs due to new information reaching the individual. For example, when a diagnosis of disability is first disclosed to parents, in many cases they are uninformed about the diagnosis and misinformation or lack of information creates high stress. But with time, parents educate themselves about the diagnosis as well as the child’s developmental prognosis and in due course they will have access to developmental services as well as social supports. All these new information and experiences will have a positive impact on parents’ first appraisal and will trigger a reappraisal process.

Cognitive appraisal is a crucial evaluative process that will mediate the thoughts, feelings, and actions of the individual in her transactions with the environment; and can evolve over time thanks to the individual’s experience. Lazarus and Folkman (1984) described several factors that influence the appraisal process. These factors can be organized in two categories: 1) Person-related factors and 2) Situation-related factors, both categories will be briefly reviewed next and are further illustrated in Figure 2.3

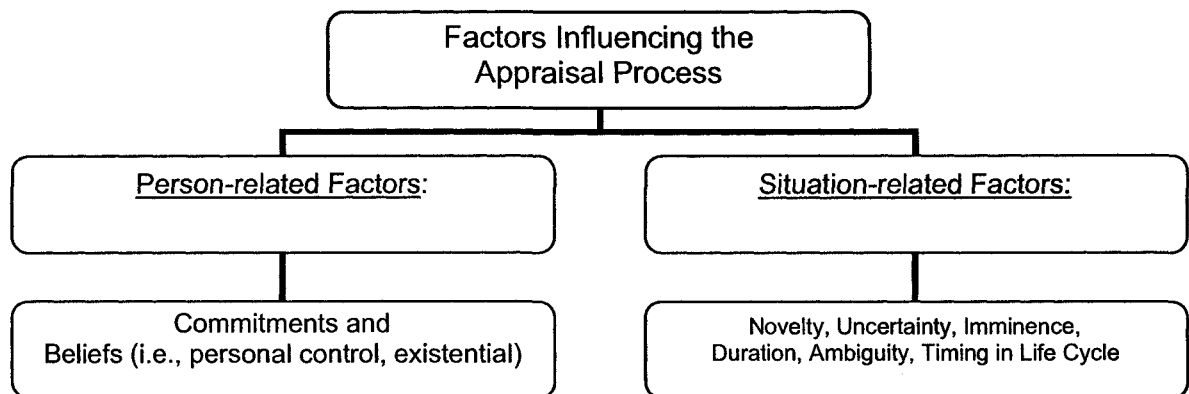


Figure 2.3 – Factors Influencing the Individual's Appraisal Process

1) Person Factors: There are two types of person factors. 1.1) Individual's commitments: What is important and has meaning to the individual and "will eventually determine what is at stake in a specific stressful encounter" (Lazarus & Folkman, 1984, p.56). The stronger the commitment the more vulnerable an individual would be if the commitment is threatened. 1.2) Individual's beliefs: "Preexisting notions about reality which serve as a perceptual lens...they determine what is fact...in the environment, and they shape the understanding of its meaning" (p.63). There are two types of beliefs: a) Personal control, i.e., the individual's degree of mastery over the environment; and b) Existential, i.e., the idea of fate or faith, the existence of a universal power.

2) Situation Factors: There are seven types of situation factors, 2.1) Novelty of the event: Whether the individual has had previous experience with the same or similar events. "...absolute novelty is quite rare. Usually the

individual has some basis for inferring meaning from a situation that he or she has not confronted before...the more inference required, the greater the possibility of an error in interpretation” (p84), 2.2) Event uncertainty: The probability of an event taking place, 2.3) Imminence: How much time the individual has available prior to the occurrence of an event, 2.4) Duration: For how long the event will exist, 2.5) Temporal uncertainty: Knowledge, or lack of thereof, about when an event is going to happen, 2.6) Ambiguity: The information about the event is unclear or insufficient. “The greater the ambiguity, the more influence person factors have in determining the meaning of the environmental configuration (p.104), and 2.7) Timing of the stressful event in the life cycle: Whether the event disrupts the expected sequence of the family life cycle, being on time or off time in the life cycle. For example, having a child prior to getting married may be considered an off time event for some individuals. Finally, in regards to the cognitive appraisal process, it is important to underscore again the fact that in some instances a mismatch may occur between the individual’s appraisal and what is actually happening in the environment. Either an event may be appraised as harmful, a threat, or a challenge when the objective reality may be giving no indication for such interpretation or, on the other hand, the individual may fail to identify harm, threat, or challenge when reality gives a clear indication of its presence.

Complementary to appraisal is the coping process.

b) Coping: Coping is defined as, “the process through which the individual manages the demands of the person-environment relationship that are appraised

as stressful and the emotions they generate” (Lazarus & Folkman, 1984, p.19), thus supporting the function and maintenance of the individual’s positive sense of wellbeing in the face of a stressful encounter with the environment. Coping involves a level of energy investment on the part of the individual, that is, “cognitive and behavioral efforts to manage specific external and/or internal demands that are appraised as taxing or exceeding the resources of the person” (p.141). When coping is effective the individual is able to solve the problem at no great cognitive or behavioral cost. Two types of coping processes have been described, a) Emotion-focused coping and b) Problem-focused coping.

During emotion-focused coping an emotion regulation to relieve the problem takes place. *Thinking* about the transactions with the environment is what best describes this type of coping. It is encompassed by “cognitive processes directed at lessening emotional distress and includes strategies such as avoidance, minimization, distancing, selective attention, positive comparisons, and wresting positive value from negative events” (p.150). During problem-focused coping an action regulation to relieve the problem takes place. *Acting* upon the environment and inward on the individual is what describes this type of coping. Coping is encompassed by efforts “directed at defining the problem, generating alternative solutions, weighting the alternatives in terms of their costs and benefits, choosing among them, and acting” (p.152).

Coping is influenced by cognitive appraisal and thus, is likewise influenced by factors found at the person or situation levels. Within the realm of the person the following four resources will have an impact on coping, a) Health and energy

- A healthy and robust person has more energy to expend on coping, b) Positive beliefs - Keeping a positive view about oneself, presence of hope regardless of adverse conditions, more use of problem-focused forms of coping versus emotion-focused forms of coping, c) Problem-solving skills - Ability to analyze the problem and come up with a plan for action, and finally d) Social skills - Ability to behave in a socially appropriate manner and to procure other individuals for support. Within the realm of the situation (i.e., environment) two types of resources will have an impact on coping, a) Social support - Individuals that provide tangible or instrumental support are available and b) Material resources - Money, goods and services. These resources are illustrated in Figure 2.4. Importantly, some personal traits, such as “internalized cultural values and beliefs that proscribe certain types of actions or feelings, and psychological deficits that are a product of the person’s unique development” (Lazarus & Folkman, 1984, p.165) may pose constraints to the individual’s ability to make proper use of the above coping resources.

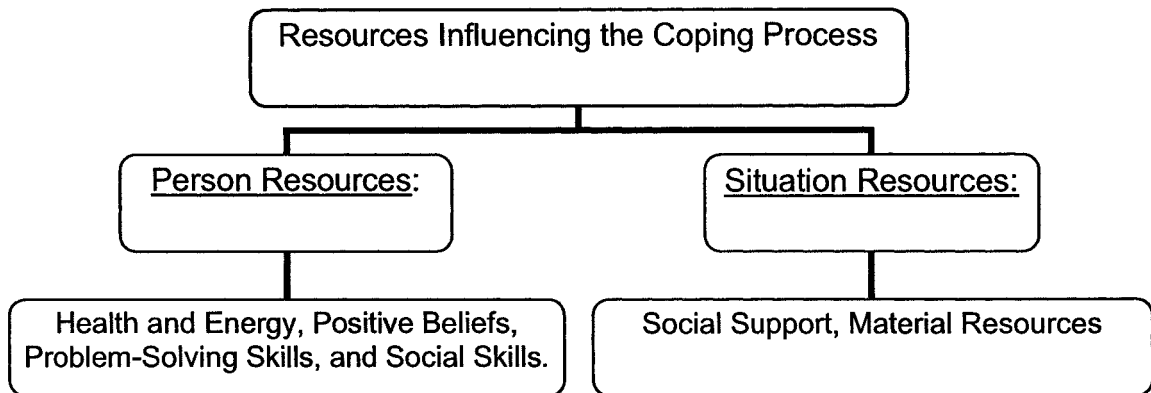


Figure 2.4 – Resources Influencing the Individual's Coping Process

The transactional model of stress and coping emphasizes that stress is a fact of life and that each person's goal should not concentrate on learning how to get rid of stress but instead, to learn how to benefit from it. Lazarus and Folkman have placed emphasis on the fact that life without stress would be "an exercise in boredom" (1984, p. 181). Their research goal is not to determine "whether stress is good or bad, but rather how much, what kinds, at which times during the life course, and under what social and personal conditions it is harmful or helpful" (1984, p.182). It is known that among the events that threaten an individual's psychological well-being, those characterized by their intense magnitude, extended durability and unpredictability are the ones that produce the most stressful experiences. Parenting a child with disabilities is a life event that falls under this category of intensity, durability and unpredictability.

The Ecological Model of Human Development: Urie Bronfenbrenner
(1979).

For the past 40 years, a more systems-thinking approach to understanding human behavior and experience has evolved. Neither the individual nor his family are seen in isolation, quite the opposite, they are seen as immersed in a complex web of rich interrelationships and multidirectional influences amongst themselves as well as with the various contexts in which their daily lives take place. Bronfenbrenner proposed that human development is a “lasting change in the way in which a person perceives and deals with his environment” (1979, p.3). This is a bioecological theory in which environment plays a decisive role on human psychological experience and growth. Besides taking a look at psychological factors, Bronfenbrenner’s theory examines the social, economic, political, and cultural factors contained in the environment.

Bronfenbrenner defined the *ecological environment* as a set of concentric structures that are found one within the other, like the Russian matryoshkas (See Figure 2.5), arranged in order of proximity to the individual’s daily life and extending far beyond the immediate environment in which the individual participates (e.g., family, community, sociopolitical state of affairs). All these structures are thought as having a strong influence on the individual and are analyzed in systems terms; that is, through the social interconnections and reciprocal influences that take place within, between, and among these structures. Bronfenbrenner adamantly criticized the importation of models originally utilized in the observation of subhuman species to the understanding of

human behavior. An approach like that, he argued, is limited to the “immediate, concrete setting containing the living creature and focuses on the observation of the behavior of one or, at most, two beings at a time in only one setting” (1979, p. 21). On the contrary, his is a model that aims at the profound examination of “multiperson systems of interaction not limited to a single setting and [taking] into account aspects of the environment beyond the immediate situation containing the subject” (1979, p. 20). The ecological model of human development describes the coexistence of 4 main subsystems: a) Microsystem, b) Mesosystem, c) Exosystem, and d) Macrosystem. The following section will briefly review each one of these.

a) Microsystem: This system is defined as the “pattern of activities, roles, and interpersonal relations experienced by the developing person in a given setting with particular physical and material characteristics” (Bronfenbrenner, 1979, p.22). Activities, roles, and interpersonal relationships are seen as the building blocks of the microsystem. The phenomenological field is of crucial importance, any given environment is composed not only by its objective, tangible properties, but also by the ways these properties are perceived by each one of the individuals who interact with and within the environment (e.g., appraisal of child development). Examples of microsystems are: Home, daycare, school, job, parent support group.

b) Mesosystem: This system is comprised of the “interrelations among two or more settings in which the developing person [or a third party close to her known as *intermediate link*] actively participates” (Bronfenbrenner, 1979, p.25).

In this way, the interconnections (i.e., network) among various microsystems form a mesosystem. Mesosystems are formed or can be extended every time the person moves into a new setting (i.e., *ecological transition*). Examples of mesosystems are: Connections among nuclear family and extended family, between parents and colleagues at work, or the connections between parents and early intervention service providers.

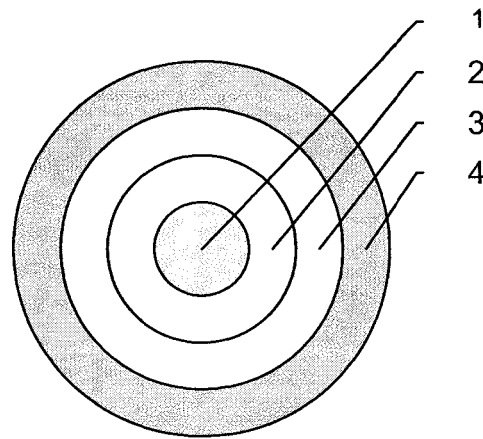


Figure 2.5. Ecological Model of Human Development

1 Microsystem, 2 Mesosystem, 3 Exosystem, 4 Macrosystem

c) Exosystem: This system refers to “one or more settings that do not involve the developing person as an active participant, but in which events occur that affect, or are affected by, what happens in the setting containing the developing person” (Bronfenbrenner, 1979, p.25). Examples of exosystems are: State Department of Education, or the early intervention program board of directors.

d) Macrosystem: This system refers to “consistencies, in the form and content of lower-order systems (micro-, meso-, and exo-) that exist, or could

exist, at the level of the subculture or the culture as a whole, along with any belief system or ideology underlying such consistencies” (Bronfenbrenner, 1979, p.26). Macrosystems are composed by ideologies of each culture’s social institutions; these ideologies have the power of giving meaning to various situations and experiences. For Super and Harkness (1999), macrosystems represent a group’s culture. Examples of macrosystems are: Catholicism, communism, capitalism, familism, collectivism.

This model emphasizes on the individual’s perceptions and how the accumulated psychological content is prone to change as the individual interacts with the environment (Bronfenbrenner, 1979, p.9). Professionals in the special education field continuously place emphasis on the fact that the developmental outcomes of a child with disabilities are closely related to the parents’ response towards disability. The parent-child dyad is of utmost importance for promoting the child’s development; this primary relationship constitutes a *developmental* system that stimulates and maintains developmental processes for each one of the members given they remain interconnected. An individual who cannot constructively respond to the experience of parenting a child with disabilities may jeopardize the child’s chances for achieving expected developmental milestones. Although his ecological model is being associated mostly to child development, Bronfenbrenner hoped that “ the ecological schema developed here can provide a base for a much needed expansion of systematic research on human development in the middle years of life” (1979, p.232).

The experience of parenting a child with disabilities is a central aspect of this study and taking a closer look at all the intertwined ecological layers described by this model of human development could support the identification of fundamental factors embedded in these of influence that may have been overlooked by previous research.

The Orthogonal Cultural Identification Theory: Eugene R. Oetting and Fred Beauvais (1990).

According to Lonner and Malpass (1994, as cited in Oetting, Donnermeyer, Trimble, & Beauvais, 1998) there may be over 175 definitions for culture in the literature of the social sciences. Culture is a concept that defines “at least some of the characteristic attitudes, beliefs, and behaviors of a group of people that share a commonly perceived cultural identity” (Oetting et al., 1998). Culture and person are constantly interacting, and the degree to which an individual abides by the group’s culturally accepted behaviors and the degree of affiliation to the group will be a manifestation of the individual’s identity (i.e., a qualitative trait) and of her level of cultural identification (i.e., a quantitative trait) (Oetting, 1993; Oetting et al., 1998).

Cultural identification, the dynamic equivalent of cultural identity is a, “Personality trait, is a persistent, long-term underlying characteristic that organizes cognitions, emotions, and behaviors. Those with high identification with a culture perceive themselves as adapted or adjusted to that culture. They see themselves as involved in the culture and as

capable and competent within it. The person with high cultural identification is more likely to see events from the perspective of that culture” (Oetting, 1993, p.33).

The orthogonal cultural identification is a social learning process theory that concentrates on the types of dynamic cultural adaptations that take place within the individual whenever cultures interact (Oetting, 1997). Cultural identification has been defined as the product of the continuous interaction between the individual and her environment, cultural identification depends on the individual’s experiences and it reflects the existence of a symbiotic relationship between the individual’s needs and the environment. According to these authors,

“Instead of culture being placed as opposite ends of a continuum, cultural identification dimensions are independent of each other, and increasing identification with one culture does not require decreasing identification with another” (1990, p.655).

This approach allows for the determination of various levels of cultural identification with more than one culture at the same time, thus, describing a more dynamic and flexible model than biculturalism or multiculturalism. The orthogonal model establishes that the level of identification with one culture is independent from the level of identification with another (See Figure 2.6), and that this is a process subject to change throughout the life span of individuals depending on their experiences. Oetting and Beauvais have stated that a high cultural identification with one culture becomes a source of strength for the

individual. Cultural identification facilitates personal growth and development and it “should be correlated with general well-being and positive personal adjustment” (1990, p.672)

A high level of identification with a specific culture is generally associated with an increased probability of engaging in behaviors that are expected and accepted in that culture; in this way, if the individual behaves as expected, members of the group will facilitate the individual's access to the society's rewards and benefits, consequently reinforcing the individual's positive feelings about himself and his abilities to be a contributing and welcome member of the group. Cultural identification creates a symbiotic relationship between the culture and the individual because while culture posits demands to the individual and the individual meets the culture's requirements through his actions, the culture also responds to the individual's actions by satisfying his personal needs (Oetting, 1993; Oetting et al., 1998). In this manner, the individual's quantity and quality of participation in a given society has a lot to do to with the individual's level of cultural identification. When actions are not rewarded by society; that is, when society does not operate as a reinforcing element for the individual by providing love, respect, social interactions, access to property, among others; the levels of cultural identification are dramatically reduced and the link between the individual and the culture is broken.

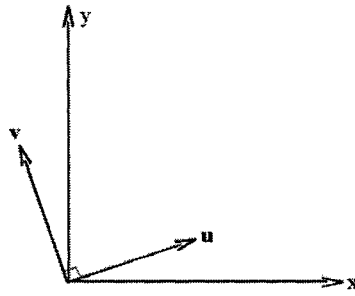


Figure 2.6 – Orthogonal Cultural Identification Model

v Culture 1, y Culture 2, u Culture 3, x Culture 4

The immigration experience

The orthogonal model of cultural identification suggests that immigration triggers a cultural merging process that results in a multidimensional, multicultural society. The immigrant's culture incorporates elements from the host culture, but both cultures in this process become culturally richer. Level of exposure to the host culture allows the immigrant the full capability to access the assets of the host culture and incorporate them as part of his own identity. Nevertheless, this process is not free from conflicts; Oetting and Beauvais (1990) have stated that,

“When a minority group with a separate and distinct culture exists in a larger environment that is strongly influenced by a majority culture, the situation could provide abundant sources of potential problems. There might be conflicting attitudes, beliefs, and values; and differences in language, dress, behaviors, and traditions” (p.636).

Immigrants, who are culturally different from the host society, have been described as adopting one of three cultural strategies as a way for adapting to the new environmental demands.

1. Separation: Also known as ethnic competition, describes the process by which the immigrants opt for staying away from the host culture by maintaining their own ethnic identity, practices, and beliefs. Economically speaking, this form of cultural adaptation has been associated with low sociocultural and psychological adaptation (Kosic, 2002) leading to permanent poverty and assimilation into the underclass (Neckerman, Carter, & Lee, 1999). Separation may be exacerbated when immigrants are racially different from mainstream society.

2. Acculturation: Describes the process by which the individual establishes connections with the host culture while keeps the connections to its original culture (Oetting et al., 1998). Acculturation refers to the cultural learning that takes place when immigrants come into contact with the host, dominant culture, producing a change on the individual's values, norms, attitudes and behaviors (Sandhu, Portes, & Sidney, 1996; Michelson, 2003). Typically, adult immigrants acculturate at a lower pace than their children, which in some cases may produce intergenerational conflicts (Vega, 1990). There are two types of acculturation (Oetting et al., 1998; Michelson, 2003):

a) *Assimilation* in which the immigrant shows an obvious preference for the host culture in detriment of their own by adopting the language, values, rituals, and by basically blending into the host culture. In this case the more the immigrant's race, religion and language resemble those of the host culture, the faster this assimilation would take place. Park (as cited in Michelson, 2003) describes how the assimilation process in the

United States is seriously limited primarily by external differences, such as skin color, or non citizenship status.

b) Integration in which the individual maintains practices of his original culture while incorporating new practices native to the host culture.

Integration may occur in spite of both cultures having opposing values, beliefs, and behavioral requirements (Oetting, 1993).

3. Marginalization describes the process by which the immigrant develops minimal interest in her own or the host culture. “Although everyone lives in a cultural context, merely living in that context does not mean that the person has a high level of cultural identification (Oetting, 1993). These individuals become, voluntarily, ostracized from society in general. Table 2.1 illustrates the cultural adaptation strategies.

Table 2.1

Cultural Identification and Cultural Adaptation Strategies

Cultural Adaptation Strategy	Cultural Identification with Culture of Origin	Cultural Identification with Host Culture
Separation	High C.I.	Low C.I.
Acculturation: Assimilation	Low C.I.	High C.I.
Acculturation: Integration	High C.I.	High C.I.
Marginalization	Low C.I.	Low C.I.

Mainstream American culture has been described as individualistic; one that stresses the value of independence, autonomy in choice and action, and social assertiveness (Bornstein & Cote, 2001). In their study, Harkness, Super, and Tijen, (2000) identified that European American parents of young children placed great emphasis on the development of those skills that had to do with being independent, smart, self-sufficient, and curious. The Latino culture, on the other hand, has been described as collectivist; one that stresses the value of interdependence, in which the well-being of the group is more important than that of the individual, the social role is fundamental for group functioning, and the family is its most valued institution (Salas-Provence, Erickson, & Reed, 2002). Although the way in which the Latino culture is being defined in this study will ambitiously attempt at representing the culture of a highly diverse population, it will primarily serve the purpose of differentiating Hispanic/Latinos from European Americans.

Review of Research on Stress, Disabilities and Culture

The relevant literature on stress, disabilities, and culture has been arranged for presentation purposes according to the following sequence:

- 1) Description of the life event: Parenting a child with disabilities,
- 2) Parent's cognitive appraisal of life event and the impact of culture,
- 3) Parent's available resources for coping with life event and the impact of culture; and
- 4) The experience of stress.

The goal of this section is to present a comprehensive and accurate research-based description of the experience of parenting a child with disabilities construed from numerous valid studies in the special education and mental health fields and to attempt at clarifying what role parents' culture may be playing in this experience. Included in this section are studies that have particularly addressed cultural differences with either culturally diverse samples in the US or studies that have been conducted abroad. Although extremely scarce, whenever possible, studies with immigrant populations will be included.

The studies presented will highlight the components of Lazarus and Folkman's (1984) transactional model of stress and coping. Likewise, components of Bronfenbrenner's ecological model of human development will be also highlighted through studies concerning cultural aspects and their impact on the parenting experience.

1) The life event: Parenting a child with disabilities.

Individuals who are expecting a child usually experience various psychological stages including, among others, the stage of developing an emotional attachment to the fetus (Valentine, 1982). Throughout the gestational period individuals progressively adapt to the physical and emotional changes that take place. Initially they must process the reality of the pregnancy; later, incorporate the reality of a developing baby, and finally prepare for the imminent parenthood. The second trimester is a very critical stage for parent-child bonding due to the fact that in the great majority of cases an amazing experience takes place for the first time: parents can feel the baby moving (i.e., quickening) and

they start fantasizing about the baby's physiognomy and resemblance, aptitudes, temperament, and so forth. Parents will eventually enjoy immersing themselves in all sorts of dreams about their child's future, and more frequently than not, in these dreams will lie implicit the fact that the child will follow a typical pattern of development. That is, the child will have no disabilities.

The research-based literature has reported that disclosure of disabilities produces a great psychological impact on parents (Strauss, Sharp, & Lorch, 1995). Some individuals have been described as going through a process of mourning the dreamed baby as part of the process of accepting the new one (Lamberti & Detmer as cited in Kroth & Edge, 1997). According to Abidin (1990) and Minnes (1988) the presence of a child with disabilities produces a stress response not only on parents as individual members of the family, but on the family as a system, affecting several aspects of its functioning. The family established *modus operandi* is altered in order to incorporate necessary changes that will fit the baby's needs.

The literature highlights several factors that are associated with an increased level of stress. In their study, Koegel and collaborators (1992) observed that when compared to mothers of typically developing children, mothers of children with autism did not experience a general type of stress as the former group did, but that there were very specific areas of the child's functioning that showed to be more challenging than others. These authors explored stress by utilizing the Questionnaire on Resources and Stress (Holroyd, 1987) and obtained a stress profile said to be steady among mothers of children with

autism. These researchers selected women from different regions across the continental United States as well as a sub sample from Germany. While the instrument is composed by 11 scales, the stress profile in the Koegel's study showed significant higher levels of stress on five of these, a) dependency and management, b) cognitive impairment, c) life span care, d) limits on family opportunity, and e) personal burden. In other words, this profile showed that mothers were primarily concerned with a) the child's ability for reaching independent functioning, b) the child's learning and thinking abilities, c) the imminent need for sustained care, d) the constraints imposed on family social, emotional, professional, and economic functioning, and d) the physical and emotional exhaustion of the caregiver. These areas of concern were also found by a replication study conducted in Peru (Suarez-Sousa, 1994).

There are several child variables that have been consistently associated with higher levels of stress, amongst which the child's behavioral problems is certainly the most frequently identified stressor (e.g., Cho, Singer, & Brenner, 2000; Hastings, 2000; Baker, McIntyre, Blacher, Crnic, Edelbrock, & Low, 2003; Hodapp, Ricci, Ly, & Fidler, 2003). Externalizing behaviors such as lying, stealing, behaving violently toward self or others, throwing temper tantrums, showing signs of hyperactivity or inattention are generally the most stressful for parents of children with disabilities (McGlone, Santos, Kazana, Fong, & Mueller, 2002) because these behaviors in most of the cases limit the access to normalized life experiences such as visiting friends, going to the park with the children, watching a movie, or having dinner at a restaurant. Consequently,

child's behavioral problems rapidly deplete parents' resources of time and energy, particularly when there is a single head of the household, and are considered to be the strongest predictors of stress (Jackson, 2000).

The child's level of functioning has been also identified as contributing to stress (Gowen et al., 1989, Abelson, 1999, Suarez-Sousa, 1994); care giving tasks become radically incremented when the child is more dependent on others for daily living activities and parents become less available for sharing time with their spouse, for leisure activities, and for social contacts outside the realm of home (Abelson, 1999) and all these are activities that have been found to be instrumental in buffering the impact of stressors. Although some studies have found that certain types of disabilities are associated with higher levels of stress as it is the case, for example, of caring for a child with autism versus a child with Down syndrome in where the former has been described as generating higher levels of stress (e.g., Noh et al., 1989); it seems that the type of disability does not contribute to stress as much as the level of time and energy that caring for the child requires, and generally speaking, children with low functioning levels are more demanding, more dependent on parents' support.

Understanding the experience of stress should not only concentrate on the child as the potential source of the parent's stress, but it ought to look at other potential sources that are having a cumulative effect upon parents' sense of wellbeing. This accumulation of stressors, known as the pile up phenomenon (McCubbin & Patterson as cited in Hobfoll & Spielberg, 1992), exert independent effects on the individual with a resultant higher level of stress and a consequent

greater impact on mental and/or physical wellbeing. Multiple sources of stress should be analyzed and addressed by the family intervention program.

2) Parent's cognitive appraisal of life event and the role of culture.

Even though the physiology of perception may be a standard process among races and cultures; the psychology of perception, as Lazarus and Folkman (1984) described on their model of transactional stress, is a highly idiosyncratic one. Although the birth of a child with disabilities creates significant changes at the core of the family system, families react differently and many report the positive aspects of parenting a child with disabilities.

For instance, an interesting study conducted by Stainton and Besser (1998) showed that in many cases children with intellectual disabilities have a positive effect on their families. In this study, parents revealed that their children were a source of joy, that the children helped the family in increasing its sense of purpose and priorities, their family members' increased level of spirituality, tolerance, and understanding toward others. Noh and his collaborators (1989), likewise, found that parents of children with Down syndrome experienced lower levels of stress than parents of children with a typical development; the former group described their children as happier and as being instigators of positive experiences. Hastings and Taunt (2002) showed a content analysis conducted by Mullins (1987) on 60 books written by parents of children with developmental disabilities which found that although significant demands and emotional stress were part of the parents' daily lives, they were keen on emphasizing how their

lives had increased in meaning and enrichment as a consequence of their children with disabilities.

Although there are some studies that have examined the positive aspects of having a child with disabilities, these are not predominant within the body of literature on parenting and disabilities. The limited number of studies focusing on positive aspects of the experience of raising a child with disabilities seems to be produced by a biased research approach to this topic. This bias refers to the tendency for approaching families with a deficits perspective leaving no room for the exploration of the positive aspects of the experience of parenting a child with disabilities (Hastings & Taunt, 2002).

Culture is another factor that may help in understanding differences in this experience. Each cultural group may offer their own explanations for why some babies are born with disabilities, how these children are to be treated, and the responsibilities and roles expected from family members and society in general (Groce as Cited in Lamorey (2002).

Part of the experience of raising a child with disabilities includes incorporation not only the child as a new family member but the concept of *disability* as well (Kobasa et al., 1982); and the manner the concept of disability is understood has a great impact on how families will adapt to the child. Avdi, Griffin and Brough (2000) from the United Kingdom, aimed at determining parents' construction of the concept of *disability* after their children were diagnosed with pervasive developmental disorder – PDD (e.g., autism). A PDD diagnosis is particularly peculiar because children are generally not identified

prior to the age of 3, and hence, there is a period in which parents may have thought that their child's development was progressing as expected; this situation creates a need for *redefining* the child after disclosure of disability. By utilizing semi-structured interviews, Avdi and colleagues identified parents' recurrent ideas one of which seemed to have a direct negative effect on parents' ability to cope: parents view the condition of *normal* and the diagnosis of *autism* as mutually exclusive, making difficult to redefine their children without a stigmatized identity.

The first encounter with the concept of disability as reaching one's family system, takes place during the disclosure of diagnosis session. This disclosure session is of paramount importance for the parent to understand the characteristics of the particular diagnosis and cope with it (Blacher, 1984; Svarstad & Lipton, 1977, both cited in Hasnat & Graves, 2000). This study will provide insightful data on how Latino immigrants were, in some cases, disclosed their child's diagnosis with a bad omen accompanying the prognosis or with a culturally insensitive joke. Health care professionals ought to keep in mind the positive effect that the disclosure of disabilities session has on parental coping when it is conducted following best practices (e.g., providing referral information).

Giving meaning to the concept of disability is a process also influenced by culture. Saetermore and collaborators (2001) reviewed several studies exploring the various meanings attached to the concept of *disability* by diverse cultural groups. Results in this study suggest that South Asians, for instance, understand disability as a punishment for sins committed in past lives by the child's parents;

Native Americans on the other hand, have a more positive outlook due to the fact that they place a considerable emphasis on the contributions that the individual with disabilities can still make to society. Other studies with Native Americans have also found that children with disabilities are equally accepted by the extended family, the community, are treated as any other member of the group, and the child's family receives a great deal of social support (Joe, 1982).

Mexican-American parents in the Saetermore's study described themselves as being *chosen* by God to raise the child with disabilities; this religious interpretation seems to better equip them to cope with this event.

Dar, Winter, and Tai (1974) examined the most excruciating issues faced by Israeli parents. Their study showed that parents were primarily concerned with the home care for the child, social embarrassment, the child's future mental ability, and the duration of the treatment; results that resemble those obtained by Koegel and collaborators (1992) principally regarding two areas: concern about the child's cognitive ability and span of care for the child. This may provide an indication of some universal concerns among parents of children with disabilities, something that this study is also interested in exploring.

The above studies share the characteristic of having been conducted with native populations. While culture of origin has been reported to continue influencing behaviors among immigrants (Bornstein & Cote, 2001); studies on immigrant populations are dramatically scarce and therefore there is no much information about how the process of acculturation to a host culture may influence the interpretation of disabilities and the experience of parenting a child

with such a diagnosis. One of these few studies was conducted by Cho and collaborators (2000), they compared immigrant Korean parents living in the US versus Korean parents living in their home country in terms of coping with the experience of raising a child with disabilities. This study found that while both groups experienced an initial crisis after disclosure of disability (e.g., some mothers in both groups contemplated suicide), the majority of Korean parents (80%) living in their home country blamed themselves for the cause of their child's disability and were subject to public signs of discrimination. Neither of these was reported by immigrant Koreans; what they did report was their access to instrumental factors that facilitated daily living (e.g., own car, free intervention services), higher levels of social support, and reported stronger bonds between husband and wife. Nevertheless, these immigrant Korean parents reported dissatisfaction with the language barrier that impeded, in many cases, direct participation in their children's intervention programs and access to other types of services.

The studies reviewed in the previous paragraph show the impact that culture has on views about disabilities. Service providers immersed in a pluricultural society, such as the United States, should become familiar with culturally-based differences in the perception and experience of parenting a child with disabilities, and that the experience may become more complex when the component of acculturation is added to the equation.

3) Parent's available resources for coping with parenting a child with disabilities and the impact of culture.

A *resource* is anything that an individual uses in order to take care of a need. Families may deplete their available resources when a stressful life event exceeds their coping resources (Floyd & Gallagher, 1997). In the context of research on stress and disabilities, a resource is anything that has been shown by research to help parents of children with disabilities in ameliorating their levels of stress, and supporting the coping process. For the purpose of better organizing this section, selected literature on resources will be presented according to Lazarus and Folkman's transactional model: a) person resources (e.g., health, positive beliefs) and b) situation resources (e.g., social support).

a) Person Resources

Person resources refer to factors that are a structural part of the self; for example, self-efficacy, religiosity, resiliency, age, and level of education.

Self-efficacy, described as the belief in one's personal mastery when facing difficult circumstances (Bandura, 1977), explains why some people facing thorny life events experience less stress. Parents of children with disabilities with high levels of self-efficacy would be more likely to seek and also get support from friends and family; they would read and learn about the disability and exhaust all possible treatment options available for their children as well as modifying their goals and expectations regarding various areas of functioning (Lovallo, 1997). Conversely, parents with low levels of self-efficacy will feel overwhelmed by the

challenges associated to raising a child with disabilities and report higher levels of stress (Jackson, 2000).

The individual's practice of rituals and religiosity are factors that have likewise been associated with successful coping among mothers of children with disabilities (McAdoo, 1995). It is important to mention that this religiosity is not associated with church attendance and hence social contact with a larger supportive community, but with the intimate conviction about the existence of a protective superior being and with all associated practices that maintain this belief.

Resilience is another resource described by McCubbins and McCubbins (as cited in Hawley & Daltaan, 1996) as helping families in resisting disruption when are facing dramatic changes and crisis; resilience assists families in coping with, enduring, and surviving stressful experiences. Hawley and Daltaan (1996) highlighted some of the factors that seem to be related to an individual's level of resilience: goodness of fit between parent and child, the practice of family rituals, a proactive confrontation of problems, minimal conflict in the home during infancy, absence of divorce during adolescence, and a productive relationship between a child and his or her mother. Research puts goodness of fit between child and parent as a risk factor for child maltreatment (Dubowitz & Black as cited in Cowen & Reed, 2002); whenever there are more differences than similarities between parent and child, the latter will be more vulnerable to suffer psychological or physical abuse. For instance, Noh and collaborators (1989) pointed up that for some individuals the parenting experience was stressful

because parents considered their children as “less attractive, intelligent or appropriate than desired (acceptability)” (p.460). This type of introspective discourse is influenced by social encounters, expectations, and cultural standards of what seems to constitute desirable. The way by which the concept of desirable is defined will influence parents’ ability to see resemblances with their own children, and will impact on the goodness of fit factor with its consequent impact on stress.

Age represents a stage in human development that correlates to certain behaviors, needs, and expectations, and in this sense it has been reported to be a resource for coping with stress; nevertheless, studies have found conflicting results. A number of studies indicate that higher stress is reported by younger parents (Baldwin et al., 1995), while others report exactly the opposite (Macias, et al., 2001). In these particular cases, conflicting results may have been a function of the sample composition and not of the age of the parents. For instance, Macias and collaborators conducted a study with a sample that was composed of parents of children with spina bifida, while Baldwin and collaborators had a sample composed of parents of children with attention deficit hyperactivity disorder - ADHD. Children with ADHD may manifest associated behavioral problems, which as it was described earlier, constitutes the most disruptive and challenging of all characteristics of children with disabilities.

Level of education is also a resource that seems to be instrumental in coping with stress. Level of education may support the individual in negotiating with the system that provides services for children with disabilities and may

support parents better understanding information about the diagnosis and the educational or health intervention programs as well as communicating with service providers who in many cases use a language plagued by professional jargon. Little (2002) conducted a study with a sample consisting of 103 parents of children with cognitive impairments, results showed that mothers with higher levels of education coped better with the parenting experience and reported lower levels of stress and lower depressive symptoms than mothers with lower levels of education. Suarez-Sousa (1994) reported similar results with a sample of Peruvian parents of children with autism.

Other person resources such as the individual's health status or subjective levels of physical energy have not yet been reported by the literature on stress and disabilities.

b) Situation Resources

Family systems theory approaches the family as a whole, a unit composed of members who are physically and emotionally interconnected, and whose behavior affect each other. These patterns of operation are commonly known as family functioning (Petr, 1998); and the literature on disabilities and stress has examined different facets of family functioning with the purpose of identifying situation resources for coping: Attachment between spouses, attachment to extended family members, support from extended family, friends, and community, financial status, and marital status.

Attachment is defined as the lifelong tendency among individuals who, when placed under conditions of stress, have the initiative of seeking physical or

emotional proximity with one or more individuals who are perceived as protective or comforting (Wood, Klebba, & Miller as cited in Boss & Mulligan 2003).

Attachment between spouses creates the foundation for a supportive relationship and may have the potential for buffering the impact of a stressful event.

Attachment still occurs among people who are physically separated, such is the case of immigrants whose extended family and friends, in most of the cases, remain in their countries of origin; nevertheless, these individuals still play an important role in providing emotional support to the immigrant. Individuals may be physically absent but psychologically present and playing a comforting or protective role (Boss as cited in Boss & Mulligan, 2003). In other cases, individuals are physically present but are perceived as being psychologically absent and this may help to understand the reasons for which some parents become detached from extended family members who are perceived as having negative attitudes toward their children with disabilities. Boss (2003) describes the concept of *boundary ambiguity*, a term used to refer to the family's uncertainty about who is *in* or *out* of the family system in regards to performing certain roles and assuming certain responsibilities within the nuclear family. Boundary clarity defines the family's identity, which is a factor that has been associated with successful coping responses (Patterson & Garwick, 1994).

Outside the sphere of the nuclear family, the literature on stress has placed great emphasis on the social, emotional and material support that is also received from friends and extended family. Extended family members include a plethora of people, among whom the most commonly examined group has been

grandparents. Studies have shown that maternal grandparents are typically perceived as providing more support than paternal grandparents, and that grandmothers in general seem to provide more support than grandfathers (Hastings et al., 2002). Furthermore, fathers of children with disabilities benefit more than mothers from the support received from grandparents (Waisbren as cited in Hastings et al., 2002), and this seems to be due to the type of responsibilities that visiting grandparents take on with the child with disabilities. These responsibilities, to great extent, resemble the types of responsibilities fathers assume the most, which are mainly responsibilities less focused on care giving chores and more devoted to playing activities—which are crucial for healthy child development. Because of this, it seems that mothers' care giving responsibilities do not get alleviated with grandparents' presence, because mothers are not getting any real respite care from them (Hastings as cited in Hastings et al., 2002).

Social support is regarded as the major supply of coping resources outside the self and family (Hobfoll & Spielberg, 1992; Baldwin et al., 1995) and is considered “one of the most influential determinants of the stress response” (Vedhara, Addy, & Wharton, 2000, p.297). According to Olstad and Søgaaard (1999), the supports that the social network provides to families can be divided in two categories, a) instrumental support and b) emotional support. Instrumental support refers to the various tangible things a family receives from friends or extended family in the event of a stressful situation (e.g., money, time to care for their children, transportation). Emotional support refers primarily to the

opportunities for one-on-one conversations about personal matters (e.g., joys, sorrows, needs) with individuals who are “quiet, attentive listeners (relatives, friends, health professionals) who do not pressure them to speak, but rather allow them to speak when they are ready” (Peebles-Kleiger, 2000, p.263). Instrumental and emotional supports are extremely important coping resources for families.

It is important to add that social support does not affect everybody in an equal manner. In reviewing the research literature, Hobfoll and Spielberg (1992) found that family social networks with too many members were associated with greater distress among families of children with disabilities, and that women benefited from less dense social networks that included only few confidants outside the family; but in general, women seem to benefit more than men from a social network (Olstad et al., 2001). Nevertheless, “there are times when supportive gestures are not felt to be satisfactory and do not bring about better functioning” (Quittner as cited in Reichman, Miller, Gordon, Hendricks-Munoz, 2000, p.281). For example, Jackson (2000) described African American women as regarding social support as a marginal predictor of stress. The physical presence of others may be more disruptive for parents who may benefit only from the psychological presence of friends and extended family. Additionally, personality traits seem to create special conditions under which the physical presence of others may be more disruptive than supportive; for instance, results from a study conducted by Hobfoll, Nadler, and Leiberman (as cited in Hobfoll & Spielberg, 1992) showed that women with low self-esteem were held back by

social support, while women with higher self-esteem benefited from greater amounts of social support. In reviewing the research literature, Hobfoll and Spielberg (1992) found that family social networks with too many members were associated with greater distress among families of children with disabilities, and women benefited from less dense social networks that included only a few confidants outside the family. Culture may be crucial in this regard, when looking at the function played by the group in collectivist and individualistic societies and the support that each member may garner from it. Parents from individualistic societies may benefit primarily from the psychological presence of their social network, while parents from collectivist societies may benefit primarily from the physical presence of their social network.

Another resource is the community, which plays also a relevant role in the coping process to parenting a child with disabilities (Patterson & Leonard, 1994). "Humans are social beings, and they have always found their strength in community" (Hartshorne, 2002, p.266). When parents believe there is a formal network of social support within the community, they will be more able to deal with stressful events (McCubbin & Figley as cited in Peebles-Kleiger, 2000). One of the most mentioned sources of support for parents are respite care services (Cowen & Reed, 2002; Abelson, 1999); defined as services that facilitate "temporary care of an individual with disabilities for the purpose of providing relief to the family of primary caregiver" (Coher & Warren as cited in Cowen & Reed, 2002). Since parents' social isolation and excessive care giving demands are related to higher levels of stress, respite care services allow parents to devote

some of their time to activities other than care giving. Abelson (1999) distributed a respite care needs assessment to 574 families of children with developmental disabilities; results indicated that the availability of respite care services would have a positive impact on overall family functioning. This study found that “the need for respite services transcends degree or extent of disability, income level, and rural and urban demography” (p.99), and that this need increases during summer time, when schools are not operating.

Researchers have observed that many parents of children with disabilities tend to isolate themselves from community and social activities as a way of avoiding difficult situations in public (e.g., child’s temper tantrums). Sometimes communities have been described as not welcoming of families with a member with disabilities, and these negative attitudes from the community make parents feel ostracized (Patterson & Leonard, 1994). For instance, encounters between families and health care providers in where parents are being told, directly or indirectly, to reduce their level of expectations about their child’s future (Franco, Poole; personal communications, 2003). Also, physical barriers to public places such as high steps, curbs, lack of ramps, small access doors, and so forth may make parents of children with disabilities feel like second class citizens (Hartshorne, 2002).

Finally, both financial and marital status create special conditions for coping with stress. Baldwin and collaborators (1995) recruited 30 parents of children with ADHD and determined that 42% of the variance in stress was explained by knowing the family income; results showed that the lower the

family's financial resources the higher the levels of stress reported. The conclusion drawn from this study was that "parents from lower socioeconomic backgrounds are apt to be at greater risk for increased stress than their more economically advantaged counterparts" (p.158). Research looking into the coping role of the parents' marital status has been consistent in identifying single mothers of children with disabilities as experiencing higher level of stress than married ones (Schilling, Kirkham, Snow, & Schinke, 1986; Olsson & Hwang, 2001).

4) The experience of stress.

"Almost anything can become a stressor, providing it is of sufficient duration, frequency, or intensity; thus, any major change can lead to stress" (Barrow & Prosen, 1981, p.5). The research-based literature exploring stress and disabilities is quite copious (e.g., Lazarus, DeLongis, Folkman, & Gruen, 1985; Bristol, 1987; Baxter et al., 2000; Cummins, 2001). Stress has been identified as being an associated variable to the experience of raising a child with disabilities; by either biological or adoptive parents, and research has found that this population of parents have statistically significant higher levels of stress than parents of typically developing children (Koegel, Koegel, & Schreibman, 1991; Ong, Chandran, & Peng, 1999; Bhagwanji & Suarez-Sousa, 2002; McGlone, et al., 2002; Esdaile & Greenwood, 2003).

One area of concern among professionals providing services to children with disabilities and their families is that stress has the potential for having a negative impact on parental skills (e.g., Abidin, 1990; Webster-Stratton, 1990; last

two cited in Baldwin et al., 1995), which can be counted in great extent as responsible for the child's poor developmental outcomes (e.g., Magill-Evans & Harrison, 2001). This direct association between stress and child's developmental outcomes is of utmost significance for professionals rendering services to children with disabilities and their families in the context of the intervention programs' level of success. Thus, the exploration of stress should not only concentrate on the child as the potential source of the parent's total level of stress, but researchers ought to look at other potential sources of stress that may be having a cumulative effect so that intervention programs can address each one of these. The total level of stress experienced by parents of children with disabilities will be a function of coping factors that were reviewed in preceding sections. The remaining of this section will take a look at the phenomenon of stress itself, which is manifested through two types of responses. One is a physiological response, which is standard. The other one is a psychological response, which is primarily idiosyncratic.

Stress: Physiological Response

The *stress* phenomenon has been abundantly studied for many years at the physiological level. One of the firsts and most acclaimed researcher on this topic was Hans Selye (1956), known as "the father of stress," who defined and coined the term *stress syndrome* and accosted the phenomenon from a physiological perspective. Selye defined stress as "the nonspecific response of the body to any demand made upon it" (as cited in Barrow & Prosen, 1981, p.5). Selye stated that, "in its medical sense, stress is essentially the rate of wear and

tear in the body. Anyone who feels that whatever he is doing - or whatever is being done to him - is strenuous and wearing, knows vaguely what we mean by stress" (1956, p.3). Numerous experiments helped him discover that stress causes changes in the structure and chemical composition of the body and that these changes could be accurately determined. Selye's *general adaptation syndrome* was the organism's response to any threats to its equilibrium, a concept that Cannon (1929, cited in Lovallo, 1997) had brought to the scientific attention with his works on homeostasis; the process by which the organism maintains its equilibrium in the face of environmental changes.

According to Lovallo (1997) Cannon noted that, "...humans have specialized sensory nerves to communicate the state of the rest of the body to the brain. The brain is able to detect non-optimal internal states and it can call a variety of mechanisms into play to compensate correctly" (p.34). With Cannon's research as background, Selye conducted systematic studies on stress as a way for understanding the effects of foreign agents that would seriously threaten the homeostasis of an organism. Throughout creative and well organized studies with animals subjected to stressful situations, Selye identified the organism's stress response for survival and for adaptation. This stress response (i.e., the stress syndrome or what he called the *general adaptation syndrome*) has three phases: a) The alarm reaction, which helps the organism by recognizing the stressor and sending signals to the body via hormones released from the endocrine glands (Barrow & Prosen, 1981); b) the stage of resistance, also called the *defense reaction*, in which the organism vigorously fights at maintaining or

gaining control over the environment; and c) the stage of exhaustion, also called the *defeat reaction*, in which the organism loses control over the threat and acknowledges defeat (Lovallo, 1997). If the organism cannot reconstitute its equilibrium, when the stressor exceeds the organism's ability to cope and adapt, a prolonged exposure to stress can produce tissue damage and also death. From his studies, Selye concluded that stress is a crucial factor in the etiology of several physical illnesses (e.g., ulcers, asthma, hypertension).

During the alarm stage the stress hormone, cortisol, is released into the bloodstream. In high levels, cortisol has the ability to suppress the activity of the immune system (Lovallo, 1997) as a way of coping with stress due to the overwhelming energy that it would demand for the organism to face the stressor and keep the immune system operative at the same time. Most people are familiar with the vital functions that the immune system is responsible for, primarily, the maintenance of tissue integrity (Humes, 2000), by protecting the organism from bacterial, parasitic, fungal, viral infections and from the growth of tumor cells; the immune system also regulates many body functions (Rabin, 1999). If the immune system loses the ability to perform its functions appropriately as consequence of high levels of cortisol, the organism may become vulnerable to foreign organic agents and consequently to various types of maladies.

Although the immune system is autonomous in its operation, it seems to be influenced, to great extent, by the individual's emotions (Felden, cited in Lovallo, 1997; Rabin, 1999). There are several studies linking stress and the

immune function in humans (Rabin, 1999). While the immune system normally drains metabolic energy from the body, when an individual faces a stressful event, the organism demands unusually higher levels of metabolic energy (Rabin, 1999). This additional consumption of energy would be temporal only when the stressful event is short-living; but when the organism faces a long-lasting stressful event it may become exposed to a long-lasting impaired immune system. Raising a child with disabilities has been previously described as potentially exposing some parents to a chronic state of stress.

Stress: Psychological Response

Lazarus and Folkman (1984) stated that, “psychological stress is a particular relationship between the person and the environment that is appraised by the person as taxing or exceeding his or her resources and endangering his or her well-being” (p.19). The literature on stress describes that the birth of a child with disabilities taxes parents’ resources for coping. Depending on the scale of this taxation, parents will experience either a high or low level of stress (Hatshorne, 2002; Gallagher et al., 1983; Koegel et al., 1992), translated into various measurable behavioral and emotional outcomes (e.g., role confusion, personal and professional goal interruption, personal burden, divorce, low self-esteem). Considering that parents’ psychological wellbeing is a crucial factor in the production of a healthy environment for a child’s development (Brazelton, 1992), and that stress could deteriorate the quality of the parent-child relationship (Donenberg & Baker, 1993), it can be concluded that stress can have a detrimental direct effect on child’s development (Magill-Evans & Harrison, 2001).

This negative impact is critical when it comes to children who are already struggling with achieving developmental milestones due to disability.

Although few studies have found no difference in stress levels between mothers and fathers of children with disabilities (e.g., Noh et al., 1989; Hastings, 2003), most studies have found that mothers experience higher levels of stress than their husbands (Suarez-Sousa, 1994; Floyd & Gallagher, 1997; Pelchat et al., 1999; Trute, cited in Padeliadu, 1998; Olsson & Hwang, 2001; Little, 2002). In many cases this is due to the personal and professional sacrifices that mothers tend to assume (Hirose & Ueda, 1990; Olsson & Hwang, 2001; Bhagwanji & Suarez-Sousa, 2002) and the duration and frequency of time demands related to the leisure and educational needs of their children (Padeliadu, 1998). The mother is usually the first family member to consider giving up work or educational goals in order to devote their available time to the child.

The predominant role of the mother in child's development is a recurrent characteristic observed across cultures, particularly those that have been described as feminine-oriented, such it is the case of many Latin American countries, where fixed and differentiated roles are tacitly assigned to men and women (Hofstede, 2004). Stewart and Bond (2002) stated that the gender factor appears to generate a "culture within a culture;" as it has been suggested earlier, the experience of stress in most cases seems to be vastly different between mothers and fathers in most of the cultures studied. For example, this is the case of various studies conducted in different European countries. In Estonia,

Veisson (2001) compared personality traits of parents of children with mental retardation with that of the norms from the general Estonian population and found that both groups differed, mothers of children with mental retardation showed higher levels of neuroticism (i.e., emotional instability) than the norm and than their husbands. In Finland, Saloviita, Itälä, and Leinonen (2003) showed that mothers of children with an intellectual disability were more vulnerable to stress due to the disability, while their spouses were more vulnerable to stress due to the level of social acceptance to the child. Mothers relied more on social/informal support, while fathers relied more on spousal support and their own strength for coping with stress. In Sweden, Olsson & Hwang (2001) compared mothers and fathers in terms of their levels of depression associated with parenting a child with intellectual disabilities and autism. Results demonstrated that in general, mothers experienced higher levels of depression than fathers. In Italy, mothers were found to be more psychologically vulnerable to the quality of the child's condition, but were found to cope better with it, while fathers were more vulnerable to the challenges that were faced by their children and were more prone to depression, anxiety and pessimistic attitudes because of it (Saviolo-Negrin, Cristante, Zanon, Canclini, Stocco, & Girolami, 1999). In Greece, mothers are the primary educators of their children and the responsibility of raising the child is often solely theirs (Padeliadu, 1998). In sum, these studies show some striking similarities regarding mothers and fathers' parenting roles and responses toward disability.

In Asian societies these responses, roles, and responsibilities are not far different from the ones observed among Europeans. Hirose and Ueda (1990) interviewed Japanese mothers and fathers of young adults with cerebral palsy. These interviews revealed that mothers' initial reaction to the diagnosis was primarily emotional and in no way instrumental for coping with the event; on the other hand, fathers' responses were realistic and instrumental in coping with the problem. As the children grew older, Japanese mothers struggled the most during infancy while Japanese fathers showed more concerns during the toddler and school years. The Korean culture deems that the 9 months of pregnancy are of great educational value for child's physical and mental development. It is due to this cultural vision of child development that Koreans self-blame when a child with developmental disabilities is born (Cho et al., 2000), particularly mothers who are the gestational carriers.

Although rearing a child with disabilities is considered to be a challenge to any parent, in any culture, it seems to be particularly challenging for parents in goal-oriented, success-thriving, and self-fulfilling industrial societies (Padeliadu, 1998) and to be predominantly more challenging for mothers.

Best Practices in Translating Psychometric Instruments

One process for expanding the universality and generalization of theories is through the replication of the findings in cultures other than the one in which they were initially developed (Kim & Lim, 1999). Researchers interested in investigating social phenomena or psychological traits across cultures should be able to either access testing instruments or to produce them in a way that is

sensitive to the target culture. Devins and Beiser (1997) stated that the “pluralistic transformation of North American society directs serious attention to the development and adaptation of culturally appropriate survey measures” (p. 797).

There are approximately 35 million Latinos living in the US (Census Bureau, 2003), making them the largest minority in the country; the projection is that for the year 2050 the number of Latinos will reach one fourth of the entire US population (Carroll, 2001). Nevertheless, there is a dearth of research and instrumentation that could support practitioners in understanding the Latino parent and his or her process of coping with the stress of raising a child with disabilities. In an effort to incorporate this population into the research activity, researchers have increased the practice of translating psychometric instruments (e.g., Solis & Abidin, 1991; Hendrickson, 2003; Carrol, 2001), but in conducting this practice little attention has been given to the translation methodology per se. Too frequently the translation process has been viewed as a “preliminary step that needs to be accomplished as expediently as possible in order to move forward to the *real* research project” (Carrol, 2001, p.213). Likewise, Chang, Chau, and Holroyd (1999) have warned about the validity of studies that utilized translated instruments with a minimal explanation of the methodology for determining the equivalences of both versions. Any research results attained with a translated instrument for which there is no information on its reliability or validity indexes should be considered inconclusive.

Translation seems to be a clear cut concept, Newmark (2003) defined it as the process by which the meaning in one text is interpreted into another language for a new and potentially different readership. Newmark also described two general domains of translation, the literary translation that refers to the sphere of the mind and creative writing (e.g., novels, poems), and the non-literary translation that refers to the sphere of reality and the world (e.g., psychometric instruments, history books). Complementing this categorization, Jakobson (as cited in Gentzler, 2001) expanded on three specific levels of translation, a) intralingual translation, which takes place when signs from one language are changed for other signs from the same language, b) interlingual translation, which takes place when signs from one language are changed for signs from other language, and c) intersemiotic translation, which takes place when signs from one language are changed for signs from a non-verbal system (e.g., from language into images).

The following section will focus on best practices for conducting a non-literary interlingual translation. This section will take a closer look at the methodologies of, 1) Forward translation, 2) Back translation, it will provide a description of the 3) Translator, and it will expand on considerations regarding the, 4) Emic and Etic perspectives when conducting a translation, 5) Focus group for checking equivalences, clarity, and cultural bias, 6) Pilot study, and 7) Cross cultural equivalence.

Non-Literary Interlingual Translation

The goal when the translation of a psychometric instrument into another language will take place is to obtain a translation that not only preserves the meaning of each item across the two languages but it maintains the integrity of the instrument (Gilmer & Tripp-Reimer, 1995). Several authors concurred that the best methodologies for producing equivalent versions between psychometric instruments in the source language (SL) to the target language (TL) are the forward translation and back translation (e.g., Auchter & Stansfield, 1997; Carroll, 2001; Chang et al., 1999; Corr & Kumari, 1997; Devins & Beiser, 1997; Ellis & Mead, 2000; Kim & Lim, 1999; Prieto, 1992; Schmit, Kihm & Robie, 2000). Some of these studies translated instruments in the psychology field, in all cases from English as a source language to various other target languages (e.g., RELATE Questionnaire, the Gray-Wilson Personality Questionnaire, the Affect Balance Scale) and implemented, additionally, either all or some of the procedures that are described next.

1. Forward Translation

Forward translation describes an interlingual translation that takes place between two languages, from the source language utilized in developing the psychometric instrument, to the target language. One or more translators could be involved in this process (e.g., committee approach). This is the simplest methodology for translating a psychometric instrument and the one most frequently utilized.

2. Back-Translation

Back translation involves the conduction of two steps. Step one requires a forward translation, step two requires that a blind translator performs an interlingual translation from the target language back to the source language. The resultant two source language versions (i.e., original and back translated) are then compared for equivalence (Brislin, 1986, cited in Carrol, 2001; Aybar-Soltero, 1999; Butcher & Gur, 1974). Although this methodology usually requires the participation of at least two independent translators, a team approach could also be utilized. Berkanovic (1980) reported that instruments translated without including a back-translation as part of the translating methodology, showed lower levels of reliability among Hispanics. The back-translation procedure is considered best practice for maximizing the accuracy of the translation and for reducing cultural bias that may be present in test's items (Aiken, 1987, cited in Samuda, Feuerstein, Kaufman, Lewis, & Stenberg, 1998).

Although both forward and back translation methodologies seem to be quiet simple, the intricate part in translating an instrument into another language is to obtain a translation that preserves the meaning of each item across both languages. The careful selection of translators and the inclusion of a focus group as part of the whole process play an important role in controlling for cultural bias in the final product.

3. The Translator

The UNESCO has defined *translator* as the individual who, “should as far as possible translate into his or her own mother tongue or into a language of

which he or she has a mastery equal to that of his or her mother tongue” (cited in Newmark, 2003). There are professional translators and those who, while working on any field other than translation, happen to be bilingual. One of the most important criterion translators must bear in mind is that of avoiding a literal translation (Banville, Desrosiers, & Genet-Volet, 2000). The aim is at preserving the holistic meaning. Herrera, Del Campo, and Ames (1993) cautioned that relying exclusively on skilled translators (e.g., certified) could yield a pretty accurate translation but one that is completely inappropriate for the target population.

It is critical to provide translators with information about the instrument, the construct that is being measured, the target population, the testing specifications, the instrument’s manual, and other pertinent information usually found in the instrument’s manual. The focus is on familiarizing translators, to the extent possible, with relevant background information about the instrument and the research project before they start the translation process (Auchter & Stansfield, 1997). When reporting research results, it is considered best practice to provide a detailed description of how the translated instrument was produced as a means for strengthening its validity (Carrol, 2001).

4. The Emic and Etic Perspectives when conducting a Translation

When conducting research with groups that are culturally different, the *emic* and *etic* perspectives are crucial in determining how much (if any) the research’s own culture (i.e., source culture) may bias his/her understanding of the culture that is the focus of interest (i.e., target culture). According to Fraenkl

and Wallen (2003), the emic perspective (i.e., the insiders perspective of reality) refers to the ideas, behaviors, and concepts that are specific to the target culture, what the researcher sees or hears; while the etic perspective refers to the ideas, behaviors, and concepts that are specific to the source culture, the external objective perspective of reality. Banville et al., (2000) have criticized the frequency by which researchers conduct studies having an emic perspective following an analysis and interpretation of results that has an etic perspective as framework.

Before starting the translation process there are two decisive issues that need to be discussed. First, to explore whether the construct of interest is relevant in the target population and so it does not become an imposed or imported etic (e.g., *stress* may be an unsuitable concept among the Yanomami tribe); and second, if the construct is found to be relevant, whether the instrument would be also relevant in the target population (Banville et al., 2000). For instance in a study conducted by Canales, Ganz, and Coscarellica (1995), it was found that the target population was not familiarized with questionnaire formats and thus, the research's instrument format had to be changed. Butcher and Pancheri (as cited in Samuda et al., 1998) suggested researchers to ask five questions prior to embarking on the translation process or when the researcher is interested on utilizing an already translated instrument and is interested on exploring its cultural relevance:

1. Does the construct exist in the target culture?

2. Is the test format (e.g., true/false, multiple choice) culturally meaningful?
3. Is the test valid in the respondent's culture?
4. Has the test been translated following appropriate procedures, such as back translation?
5. Are the response formats equivalent for all languages used?

Responding to these questions will provide a clearer idea about the level of cultural relevance of the translated instrument.

5. Focus Group for Checking Equivalencies, Clarity, and Cultural Bias

A focus group is formed by a group of people who, with the help of a facilitator, will voice their opinions about the quality of the translated instrument. When revising a translated instrument, members of a focus group are selected according to the following criteria, a) they do not necessarily need to be bilingual, but they must be proficient in the target language and b) they must be native from the target population or knowledgeable about the target population's culture. For example, in translating an anxiety stress scale, Daza (2000) utilized a focus group panel of native bilingual individuals from the community to check for colloquialisms, slang, and phrases that would make the understanding of the items too complex. The number of members in the focus group is not relevant in the sense that no statistical analysis will be conducted; yet, the number of participants is something that needs to be discussed beforehand and be based on the objectives of the study (Simon, 2002). With the help of a facilitator, the group is in charge of reviewing the tentative final translated version, make notes

on the document, and provide feedback about its general outlook (Banville et al., 2000). The inclusion of a focus group should be considered best practice in improving the overall quality of a translation.

6. Pilot Study – Field Testing

A pilot study is conducted in order to determine the equivalence of the two language versions. The goal of this pilot study is to sample at least 30 bilingual individuals, representative of the target population, and have them answer both versions of the instrument successively (Carrol, 2001) in order to be able to run statistical analysis to determine content and concurrent validity, as well as reliability tests (Banville et al., 2000). In this case the English version is utilized as criterion.

7. Cross cultural equivalence

In 1988, Fleherty and collaborators (as cited in Gilmer & Tripp-Reimer, 1995) proposed five cross-cultural equivalences to be determined in the process of translating a psychometric instrument:

1. Content equivalence: To ensure that the content in each item in the instrument has consistent cultural relevance between the source and target populations.
2. Semantic equivalence: To ensure that the meaning of each item remains conceptually and idiomatically the same between the source and target populations.
3. Technical equivalence: To ensure that the methods of assessment (e.g., interviews, observations, self-report) elicit comparable data in

both populations. It is important to pay attention to subtle differences in the administration of the instrument.

4. Criterion equivalence: To establish the normative interpretation of the variable to be studied for each population.
5. Conceptual equivalence: To ensure that the same theoretical construct is being measured in both populations.

The authors provided a very interesting example on how one item can have two very different connotations among different populations. In this case the item “I see things when others do not” was originally used to assess the presence of psychotic tendencies among the US population. When this same item was literally translated respondents from the target population thought that this item suggested a very creative nature or talent, something that was, on the contrary, highly desirable.

Determinations of the five equivalences would support the development of a translated version that would be culturally relevant to the target population for data gathering purposes. A cross cultural team composed of native source language bilinguals (NSLBs) and native target language bilinguals (NTLBs) would be ideal.

Conclusions

This chapter aimed at presenting a summary of the literature on stress and disabilities as well as relevant literature on best practices in the translation process of psychometric instruments. The theories providing a theoretical framework for this study were presented. Knowing that an individual’s culture is

considered to be the “framework that guides and bounds life practices and through which actions are filtered and checked as individuals go about daily life” (Lynch & Hanson, 1998), culture may have a dramatic influence in the appraisal process of having a child with disabilities and the concomitant impact on the experience of stress. This study was built on the premise that for any parent the experience of having a child with disabilities may be a stressful one, regardless of the parent’s various demographic characteristics (e.g., socioeconomic status, gender, culture). Nevertheless, this study has assumed that the parent’s culture (i.e., individual’s macrosystem), which has influenced the individual’s personal history at the micro-, meso-, and exosystem levels in peculiar ways and will still influence his behavior at the present time, will serve as a filter for his appraisal of the experience of parenting a child with disabilities. In this regard, this study assumed that Latino and American parents would report different levels of stress. Research in this area may expose some significant differences in coping styles that could be applied cross-culturally. As Brislin (1976) stated, “Cross-cultural research can make contributions to theory development by identifying groups of people who seem not to behave according to established theories and by increasing the range of independent variables available for study in any one culture.” This study tried to compensate for some limitations in the current literature, the most relevant ones being that many studies have not been inclusive of fathers and of culturally diverse populations such as first generation immigrants, which in most cases are undocumented. The following chapter will present detailed information regarding the methods utilized in this study.

CHAPTER III

METHOD

Introduction

The two purposes of this study were to conduct a preliminary validation of a Spanish version of the Questionnaire on Resources and Stress for Families with Chronically Ill or Handicapped Members – QRS (Holroyd, 1987) and to explore the relationships among stress, disabilities, and culture in a group of primarily undocumented immigrant Latino and European American parents of young children with disabilities. An exploratory correlational research design was selected in order to explain the relationships among the variables of the study (Fraenkl & Wallen, 2006).

This chapter describes the design of the study, the setting, the research participants, the instruments utilized for data collection, the procedures in the main study, data analysis, and the descriptive and inferential statistics that were utilized. Two research questions and one hypothesis guided this study:

Research Question 1: What are the preliminary coefficients of reliability and validity of the Spanish Questionnaire on Resources and Stress?

Research Question 2: What relationships exist among stress, cultural variables, and demographic variables in a sample of immigrant Latino and European American parents of young children with disabilities?

Null Hypothesis: There is no statistically significant difference in the levels of stress between Latino and European American parents of children with disabilities.

The inferential statistics utilized to address the research questions and the hypothesis were Pearson Product Moment correlation, Spearman's Rho correlation, t-Test for independent samples, and multiple regression. At the end of this chapter conclusions will be presented.

Design of the Study

This exploratory correlational study was conducted in two stages. The first stage comprised the conduction of the preliminary validation of the Questionnaire on Resources and Stress (Holroyd, 1987). The second stage was devoted to the analysis and exploration of the associative nature of the outcome variable stress with the demographic and cultural predictor variables.

Setting

The settings targeted for the recruitment of participants were local agencies in the state of Oklahoma that were providing various types of services to families of children with disabilities. Organizations that were instrumental in recruiting primarily European American parents were the following: Down Syndrome Association of Central Oklahoma (DSA), Family Voices of Oklahoma, Autism Society of Central Oklahoma (ASOCO), Oklahoma Parent Network, and

Parents of Autistic Children (PAC). Organizations that were instrumental in recruiting primarily Latino parents were the Toni Reyes Child Developmental Center, the Latino Development Community Agency, and OK Mamás - Hispanic Parent Support Group. Some of the services provided to families were fundamentally informative, about educational and health topics, while others provided parents a variety of services such as legal counseling, referral, and medical services. By the time of the study, the state of Oklahoma had been recently labeled an emerging Hispanic state, meaning that the Hispanic community had grown 200% or more during the previous year (Campos-Flores & Fineman, 2005).

Participants

This study targeted Latino and European American parents of young children diagnosed with a disability and who at the time of the study were receiving early intervention or special education services. For the selection of participants this study utilized a purposive sampling method (Fraenkl & Wallen, 2006). This study did not include all individuals who voluntarily made themselves available but only those who reunited the inclusion criteria and who were considered to be representative of the target population. The criteria for inclusion were as follows: First, the participant had to be the biological or adoptive parent of a young child with an identified disability (e.g., orthopedic impairment, mental retardation, autism). Second, the child had to be receiving early intervention or special education services. Third, the individual identified himself or herself as Hispanic/Latino or European American. For Latinos, a fourth criterion existed:

these individuals had to be U.S. citizens, legal residents, documented (e.g., H1, F1, J2 visas) or undocumented immigrants. No refugees were included in this study mainly because immigrants and refugees differentiate in their reasons for leaving their home countries (e.g., persecution for political beliefs) which can have a profound impact in the process of acculturation and, most importantly, the sources of stress experienced may vastly differ between both groups (Bornstein & Cote, 2001).

Participants were informed about the study through the organization of their affiliation by either a posting on their webpage, e-mail, regular mail, or through a presentation conducted by the author during one of their monthly meetings. Individuals interested in participating in the study contacted the researcher personally. At no point did organizations provide the author contact information of their members.

Data were collected in either one of two ways. First, participants received by mail all the research materials and second, participants set up a day and time for a personal interview to be conducted in a place of their choosing. In all cases, parents received the same materials: a) Two copies of the Letter of Informed Consent, one for the parent to keep and the other for the researcher; b) the Parent Survey (See Appendix B), and c) the compensation for participation, which was mailed to parents after reception of materials or was delivered at the beginning of the personal interview. Compensation was always an age-appropriate developmental toy, but this varied in that parents were given the option of choosing according to the developmental area of their interest. For

example, parents interested in stimulating the child's fine motor skills were given a set of Play-Doh.

Instrumentation

The Parent Survey was the main instrument utilized for data collection purposes. This survey was composed of three sections. The first section contained the Questionnaire on Resources and Stress – QRS (Holroyd, 1987) utilized to gather data on the global level of stress, personal stress, family stress, and index case stress; the second section of the Parent Survey contained the Orthogonal Cultural Identification Scale – OSCIS (Oetting & Beauvais, 1990) utilized to gather data on cultural identification with own culture and cultural identification with host culture; and the third and last section contained a set of additional questions collecting data on demographic and additional cultural information. Each one of these three sections is further reviewed next.

1. The Questionnaire on Resources and Stress - QRS

The Questionnaire on Resources and Stress - QRS was developed to measure “stress in families who are caring for ill or disabled relatives” (Holroyd, 1987, p.1). This questionnaire determines the impact, in terms of stress, that an individual with disabilities has on members of his or her family. There are two versions of the QRS; the original version which is comprised of 284 items and the short version containing 66 items. Both versions have dichotomous items, requiring from the respondent to choose between a true/false answer. These items yield quantitative data by assigning one point per item if answered in the expected direction. According to Holroyd, each item has been designed to

accommodate any gender or age of the respondent and to reflect the respondent's capacity to cope with the presence of a relative with disabilities.

This study utilized the short version of the QRS. The 66 items are grouped in 11 scales of 6 items each (See Table 3.1). These 11 scales can be organized in three broad categories of stress (i.e., personal stress, family stress, personal index stress) presented in Table 3.2. The written directions on the instrument emphasize answering all questions, even those that seem not applicable to the respondent's personal situation.

Table 3.1

QRS Scales and Component Items

Scale	Items
Scale I: Dependency and Management	1, 8, 23, 33, 51, 62
Scale II: Cognitive Impairment	5, 13, 29, 30, 44, 50
Scale III: Limits on Family Opportunities	7, 11, 15, 26, 40, 56
Scale IV: Life Span Care	12, 14, 21, 37, 42, 43
Scale V: Family Disharmony	3, 10, 36, 45, 57, 60
Scale VI: Lack of Personal Reward	6, 28, 32, 39, 54, 58
Scale VII: Terminal Illness Stress	9, 19, 27, 41, 52, 55
Scale VIII: Physical Limitations	18, 22, 25, 53, 65, 66
Scale IX: Financial Stress	20, 34, 38, 46, 47, 59
Scale X: Preference for Institutionalization	4, 16, 17, 35, 48, 49
Scale XI: Personal Burden for the Respondent	2, 24, 31, 61, 63, 64

According to Holroyd, a respondent may be able to complete the QRS in less than an hour. Total scores below a T-score of 60 may indicate that the respondent answered not significantly different from control groups.

Internal Consistency - Reliability

The author reported an overall Kuder-Richardson internal consistency for the long version at .96 and for the short version at .85; nevertheless Holroyd (1987) suggested to be cautious when using the short scales because reliability estimates tend to be lower for these shorter scales.

Table 3.2

QRS Composite of Stress – Component Areas

Area of Stress	Scales
Personal stress	4, 6, 7, 10, 11
Family stress	3, 5, 9
Index case stress	1, 2, 8

Content validity

Content validity was determined with a pool of subject matter experts who reviewed a selected pool of items. “The criterion validity of the studies [24 in total] have demonstrated capability of QRS scores to differentiate groups representing different populations, different diagnoses, different external criteria of ‘stress,’ different situations, and different cultures, as well as its utility as both predictor and criterion of stress” (Holroyd, 1987, p. 69).

Scales

The following are the descriptions for each one of the 11 scales of the short version of the QRS,

Scale # 1- Dependency and Management: Items in this scale reflect stress due to the degree to which the respondent is involved in the provision of care for the child and the ability the respondent possesses in assuming control over the child's behavior.

Scale # 2 – Cognitive Impairment: Items reflect stress due to the child's cognitive deficits and potential for learning as well as the child's development of skills that are conducive to independent living.

Scale # 3 – Limits on Family Opportunities: Items reflect stress due to having to forgo opportunities for jobs, education, social activities, and any other activities conducive to personal growth.

Scale # 4 – Life Span Care: Items reflect stress produced due to concern about extended care.

Scale # 5 – Family Disharmony: Items reflect stress due to emotional disturbs among family members such as conflicts with no resolution, the inability to include the child in family activities, and a family atmosphere of rejection and resentment toward the child or other family members.

Scale # 6 – Lack of Personal Reward: Items reflect stress due to lack of personal gratification for the roles assumed in life (e.g., parenthood).

Scale # 7 – Terminal Illness Stress: Items reflect stress due to child's health status.

Scale # 8 – Physical Limitations: Items reflect stress due to child’s health, and child’s ability to take care of own physical needs like feeding, toileting, and ambulation; as well as the child’s ability to participate in sports or other types of outdoor activities.

Scale # 9 – Financial Stress: Items reflect stress due to inadequacy of income, of housing, and the cost of care for the child.

Scale # 10 – Preference for Institutionalization: Items reflect stress due to an expectation that the patient’s condition will worsen, that the family and respondent will be more burdened in the future, and that institutionalization or living away from home is an option to be considered.

Scale # 11 – Personal Burden for the Respondent: Items reflect stress due to the level of physical and emotional energy invested in caring for the child.

The short version of the QRS has been amply utilized to measure stress among parents of children with disabilities (e.g., Baldwin et al., 1995; Floyd & Gallaguer, 1997; Hastings et al., 2002; Minnes, Graffi, Nolte, Carlson, & Harrick, 2000) and it was developed primarily as a screening device based on factor analysis of the original 284 items. Additionally to Holroyd’s short version, there are other short forms of the QRS that have been developed by other researchers (e.g., Friedrich, Greenberg, & Crnic, 1983; Salisbury, 1986; Inanami, Ogura, Nishi, Onishi, Takayama, & Kusunoki, 1985; Strobino as cited in Holroyd, 1987). The decision to use the short version of the QRS in this study was based principally on issues of time economy for the respondent. The full QRS version contains 284 items that could have either deterred parents from answering the

instrument on return it to the researcher on a timely basis. This decision also responded to the suggestions provided in the literature of survey methodology and cognitive processes which indicate that respondent's comprehension decreases as the number of items increases (Sudman, Bradburn, & Schwarz, 1996).

Spanish Version of the Questionnaire on Resources and Stress

A Spanish version of the full QRS does exist. This version in Spanish was developed by Holroyd in collaboration with Dr. Endronkin-Braun and Dr. Ortiz in 1988. A copy of this Spanish version was facilitated by Dr. Holroyd; however, she did not know whether this Spanish version had been subjected to any pilot studies for determination of its reliability or validity coefficients (Holroyd 2003, personal communication). Attempts at communicating with Dr. Endonkrin-Braun with the purpose of obtaining information regarding the validation process of the translated instrument were unsuccessful. This Spanish version possessed several structural challenges that prevented its immediate use for this study. The first limitation was the usage of Mexican regionalisms that may not have been easily understood by Spanish speakers from other parts of Latin America (e.g., item 269: “_____ tiene que usar un *chata* or[sic] un panal”). Second, there were several items that had been literally translated, and although the idea was preserved, it was not appropriate Spanish grammar for sentence construction (e.g., item # 23: “Siempre vigilo asegurarme de que _____ no se haga dano fisico a si mismo o a otros,” instead of “*Siempre vigilo que _____ no se haga daño o dañe a otros,*” item # 175: “En comparision con otros personas, pagamos

mucho dinero en cuidados medicos” instead of “*En comparación a otras personas, nosotros pagamos mucho dinero por los cuidados médicos*”). Third, in all words that should have been written with the Spanish letter ñ this was replaced with the letter n (e.g., item 247: “Es mas facil para nuestra familia hacer cosas con gente que conocemos que con estranos” instead of “*Es más fácil para nuestra familia hacer cosas con gente que conocemos que hacerlo con extraños*,” item 273: “_____ necesita ayuda en el bano” instead of “_____ *necesita ayuda en el baño*”). Fourth, there was a total absence of grammatical accents (e.g., atencion instead of *atención*), and other small details such as two words written without space in between (e.g., item 84: “Conforme el tiempopasa, pienso que va a requerir mas y mas esfuerzo para cuidar a _____” instead of “*Conforme el tiempo pasa, pienso que va a requerir más y más esfuerzo cuidar a _____*,” item 94: “Podemospagar la atencion especial que necesita _____” instead of “*Podemos pagar por la atención que _____ necesita*”) or sentences with some words in English or misspelled words (e.g., item 269: “_____ tiene que usar un chata or un panal” instead of “_____ *tiene que usar una chata o un pañal*”, item 190: “Creo que _____ debe salir de casa tan frecuentemente como otros en la familia” instead of “*Creo que _____ debe salir de la casa tan frecuentemente como otros miembros de la familia*,” item 155: “_____ es sobreprotejido” instead of “_____ *está sobreprotegido*”).

In a study conducted by Berkanovic (1980), in which a translation of a psychometric instrument was performed, it was reported that “differences between the Spanish and English version in the idiomatic quality of the interview

items, while not affecting meaning, appear to have affected the seriousness with which the interview situation was perceived” (p.1273). The reduced quality of a translated psychometric instrument seems to have the potential for triggering negative attitudes among participants, who may perceive the study as lacking the required seriousness or professionalism. Due to the previously described limiting structural challenges in the existent Spanish version of the QRS, it was considered appropriate to produce an entirely new Spanish version following best practices.

2. Orthogonal Cultural Identification Scale

The Orthogonal Cultural Identification Scale – OCIS (Oetting & Beauvais, 1990; See Appendix B, items 88 to 93) is an instrument that includes attitudinal as well as behavioral items and can be administered across cultures (Oetting et al., 1998). OCIS can measure cultural identification with 5 different cultural groups: Asian, Anglo, Latino, African American, and Native American. Its internal consistency has been reported by its authors at .80 to .89. Other studies have reported internal consistency coefficients at .66 to .72 (Johnson, Wall, Guanipa, Terry-Guyer, Velasquez, 2002). Respondents can independently report cultural identification, or lack of thereof, with each of the cultural groups presented (Oetting & Beauvais, 1990), in this way OCIS assess the “strength of a person’s links to a particular culture” (Oetting et al., 1998, p.132).

The instrument is comprised of three types of items, or levels of cultural identification, which ask the respondent about the following, a) level of identification with the specific way of life of the culture (Level 1 – L1), b) level of

involvement in cultural activities and traditions (i.e., active participation) (Level 2 - L2), and c) level of perceived and expected success in the culture (i.e., feelings of capability, respect, and competence in the culture) (Level 3 – L3). Each level of cultural identification is comprised of two questions, one that refers to the present time and the practices and believes of the respondent's nuclear family and the other that refers to the respondent's childhood and the practices and believes of his parents. All items are written in general terms in order to be free from specific cultural content (e.g., "Does your family live by or follow the Latino way of life/the Anglo way of life") and each one has four possible answers ranging from Not At All (1 point) to A Lot (4 points); scores range from 6 (i.e., lowest level of cultural identification) to 24 (i.e., highest level of cultural identification). High cultural identification with a given culture is identified by an average score per item of 3 or more, medium identification by an average score of 2, and low identification by an average score of 1. When responding about two cultures, combinations of low/low indicate no cultural identification with either culture, while high/high indicates the respondent's strong biculturalism (Oetting & Beauvais, 1990, p.668). For this study, participants answered each item for the two cultural groups represented by the sample; that is, the Hispanic/Latino and the European American cultures.

3. Demographic Survey

Twenty three items from the Parent Survey (See Appendix B, items 67 to 87 and 94 to 98b) gathered fundamental demographic information and explored the behavior of variables that were identified in the literature as relevant to the

experience of stress. These demographic variables were, a) gender of the parent (Floyd & Gallaguer, 1997; Pelchat et al., 1999; Suarez-Sousa, 1994), b) marital status (Schilling et al., 1986), c) socioeconomic status (Baldwin et al., 1995; Jackson, 2000), and d) health status and educational level (Olstad et al., 2001, Selye, 1954, Rabin 1999). Other variables that are not included in the literature of disabilities and stress but were considered to be of relevance for this study were, a) subjective appraisal of life satisfaction, b) subjective appraisal of child development, c) number of working hours, d) country of origin, and e) number of years living in the United States. Demographic variables relevant to children with disabilities were: a) gender, b) age, and c) diagnosis (Abelson, 1999; Abidin, 1990; Koegel et al., 1991; Minnes, 1988).

Procedures

This section is divided in two parts. The first part describes the followed procedures aimed at responding Research Question # 1: What are the preliminary coefficients of reliability and validity of the Spanish Questionnaire on Resources and Stress – short version? The first part is divided in three sections:

- 1) Translation of the QRS into Spanish
- 2) Field Test – Spanish short-QRS Potential Cultural/Language Bias, and
- 3) Preliminary Validation of the short Spanish QRS.

The second part describes the followed procedures aimed at responding Research Question # 2: What relationships exist among stress, culture, disabilities, and demographic variables in a sample of immigrant Latino and European American parents of young children with disabilities?

4) Main study

The second part also describes testing the study's null hypothesis: There are no differences in the levels of stress between Latino and European American parents of children with disabilities.

1. Translation of the QRS into Spanish

Three steps were undertaken with the purpose of conducting the non-literary interlingual translation of the Questionnaire on Resources and Stress. The first step consisted of the recruitment of two native target language bilinguals (NTLB) to conduct translations independently. Following recommendations from Herrera and collaborators (1993) native members from the target population (i.e., Latino culture) were recruited, one of whom was a professional translator. A sociologist and a third year medical resident served as translators. Each one was provided with a copy of the English QRS and with information about the psychological construct measured by this instrument (i.e., stress), the specifications for responding the instrument, as well as the characteristics of the target population (Auchter & Stansfield, 1997). Each translator had approximately 2 weeks to complete the assignment. The direction that was given emphasized on conducting a forward translation while keeping in mind the usage of standard Spanish and avoiding literal translations (Banville et al., 2000). It

was very important to avoid using words that may have been characterized as regionalisms from their country of origin.

The second step consisted on comparing and merging both Spanish versions into a third one (i.e., reconciliation). Following recommendations from Fleherty and collaborators (as cited in Gilmer & Tripp-Reimer, 1995), the main objective of this procedure was to ensure that the content of each item had consistent cultural relevance between the source and target languages (i.e., content equivalence). This step was conducted by the main researcher and the merging guiding criteria were: a) produce the simplest and clearest sentence, b) select the most culturally neutral words, and c) ensure that the meaning of each item remained conceptually and idiomatically the same between both languages (i.e., semantic equivalence).

The third step required the participation of a third blind NTLB; in this case the translator was a graduate student from the University of Louisville, College of Education and Human Development, who held a degree in the field of language translation and interpretation. This NTLB executed a back translation of the reconciled Spanish version into English. Directions were the same as the ones provided in the conduction of the forward translations. Once completed, the resultant two versions of the QRS in English were compared for equivalence by the author (i.e., the original QRS and the back-translated version) (Aybar-Soltero, 1999; Butcher & Gur, 1974). Both versions were similar in content and sentence structure; the main differences were found in choice of words. Final proofreading helped in correcting any additional errors that were neglected up to this point.

2. Field Test: Cognitive debriefing of the QRS in Spanish for Potential Cultural/Language Bias

The monthly “La Clínica de la Mujer Latina” (i.e., Clinic for the Latino Women), is a free breast and cervical cancer education and screening program for Hispanic/Latino women in Oklahoma City. This program has been collaboratively organized by the Oklahoma State Department of Health, the Latino Community Development Agency, the Oklahoma City-County Health Department, the Central Oklahoma Susan G. Komen Foundation, Project Woman Inc., the Oklahoma Breast Care Center, and Women of the South. “La Clínica de la Mujer Latina” program has been organized for the past few years and it is well known by members of the Latino community of Oklahoma City. Every month the clinic takes place at the headquarters of the Latino Community Development Agency. Women gather on the first floor, in a fairly large and well lighted room, in which each one waits an average of 25 to 30 minutes before a nurse comes and picks them one by one to proceed with their medical check up.

The researcher contacted the program’s coordinator and requested permission for conducting field testing of the QRS in Spanish during one of their monthly meetings. The request was granted and a visit was scheduled for the next screening. The author explained to potential participants about the purpose of the study in very generic terms and the reason for field testing the QRS in Spanish. It was made explicit that their participation was utterly voluntary; that it had nothing to do with their ability to access the medical service. Fifteen individuals, eleven Latino women and four of their spouses in attendance, agreed

to review the materials which consisted of a two-page document containing the instrument's directions plus 22 of the 66 items. The instrument had been divided ahead of time in three parts: a) Items 1 to 22, b) items 23 to 44, and c) items 45 to 66, and these were randomly assigned to participants.

Members had about 20 minutes to go through the items and to make any marks or comments regarding their general quality, grammatical structure, level of complexity, and format. For the purpose of determining item comprehension, retrospective verbal protocols were utilized (Sudman et al., 1996) with the participants. These retrospective protocols requested from participants to explain verbally what the item meant (i.e., retrospective thinkalouds). By using retrospective verbal protocols, two comprehension-related issues were explored; first, the literal meaning (i.e., semantic analysis) of the items was evaluated according to the following: a) whether the wording of each item was clear (i.e., structural ambiguity), and b) whether the words were easily understood (i.e., lexical ambiguity). Second, the pragmatic meaning (i.e., intention) of the items was evaluated. This meaning was important to the extent that it helped to identify socially threatening or irrelevant items (Sudman et al., 1996). For instance, item 31 reads as follows: "Sometimes I need to get away from the house," and although a respondent may agree with this statement he may be inclined to mark "False" only because he/she may consider that acknowledging the fact of wishing to get away from the house would be socially unacceptable. Two of the Butcher and Pacheri's questions were randomly asked to various individuals, wording was adapted for this purpose:

1. Does the construct (i.e., stress – *estrés* in Spanish) exist in the target culture?
2. Is the test format (e.g., true/false, multiple choice) culturally meaningful?

The main goal of this activity was to ensure that the inner structure of the original instrument was well replicated in the Spanish version and that there were no culturally biased elements (e.g., unfamiliar format) that could have affected parents' responses. As Fowler (1995) indicated, the process of listening to people comment about the instrument provides the researcher with a new way to look at it and to broaden the understanding of the constructs that are being studied. In total, the activity lasted for about two hours, with participants coming and going. All written materials from the 15 individuals who ended up participating were kept for further analysis.

3. Preliminary Validation of the QRS in Spanish

This section was implemented keeping in mind what Brislin and collaborators (1973), suggested "...a previously translated test by no means constitutes a license to apply it without first carefully considering its validity and reliability for its current cross-cultural use" (as cited in Solis & Abidin, 1991, p. 372). Similarly, Fowler (1995) suggested a field pre-test before getting into a full scale survey with people that share similar characteristics to those who have been targeted to participate in the main study. In conducting a preliminary validation of the Spanish version of the QRS, eighteen Latino parents were recruited from the Toni Reyes Bilingual Child Development Center. This is an

Early Head Start program operating in the headquarters of the Latino Community Development Agency and serving primarily Latino families. The Director of the center facilitated walk-in access to recruit parents during a three-day period in which the purpose of the study, the significance of their participation, and the compensation for participating in the study were explained. The recruitment took place in the late afternoon, as parents came to pick up their kids and waited for a while until their kids were ready to leave.

The selection criteria were kept fairly similar to the criteria used in selecting the sample for the main study: First, the individual had to be the biological or adoptive parent. Second, the individual identified himself as being Latino, either a U.S. citizen, resident, or undocumented immigrant but not holding a refugee status.

All the interviews were conducted in the parents' home, on average these took approximately 30 minutes to complete, and the following materials were given at the time of the interview: a) the Letter of Informed Consent, b) the QRS in Spanish, and c) the compensation. Most Latino parents were monolingual and participated in the determination of the instrument's reliability only. Twelve Latino bilingual parents participated in the determination of the coefficient of validity by responding to the QRS in English on a second opportunity (i.e., criterion-related evidence of validity). In these twelve cases, parents were mailed the QRS in English—about three weeks after responding the QRS in Spanish—with a pre-paid, self-addressed envelope to mail back the instrument to the researcher. A

follow-up phone call was performed to remind parents mailing back the materials after failing to do so in more than a 2-week period.

The Statistical Package for the Social Sciences (SPSS) was utilized in the generation of a data file for computer analysis.

Reliability

Reliability “refers to the consistency of the scores obtained” (Fraenkl & Wallen, 2006). In order to address issues of reliability of the QRS in Spanish (Research Question # 1), the split half method of internal consistency was utilized. Items in the QRS in Spanish were divided in two groups, one composed by odd items and the other by even items. The correlation coefficient between these two sets of scores was determined. With the split-half procedure the researcher was able to determine whether these two halves of the instrument yielded similar results.

Validity

Validity “refers to the appropriateness, meaningfulness, correctness, and usefulness of the inferences a researcher makes” (Fraenkl & Wallen, 2006, p. 150) based on the instrument utilized. A valid instrument is said to be actually measuring what it intends to measure. In order to determine criterion-related evidence of validity (Research Question # 1), the predictive validity methodology was utilized. To obtain evidence of predictive validity participants were first given the QRS in Spanish and three weeks later the QRS in English. The validity coefficient (i.e., correlation coefficient) was calculated in order to determine the

degree of the relationship between the scores individuals obtained on the QRS in English and in Spanish.

4. Main Study

Fraenkl and Wallen (2003) stated that a correlational study “describes the degree to which two or more quantitative variables are related, and it does so by using a correlational coefficient” (p.335) A correlational study attempts at determining the association between variables; in this particular case, the association among stress, disabilities, culture, and a set of demographic and cultural variables.

In order to address Research Question # 2 and to test the non-directional research hypothesis, data were collected in two different ways. First, one group of parents requested to receive by regular mail the following research materials: a) a letter with the directions for navigating throughout the materials that were submitted, b) the letter of informed consent, c) the Parent Survey, and a d) pre-paid self-addressed envelope. Second, the other group of parents requested to be interviewed in person, primarily in their homes; research materials were the same with the exclusion of the first item. The duration of personal interviews ranged between 60 minutes to 4 and a half hours, but on average the interviews took about 2 and a half hours to complete. Reminder phone calls followed for the mailing group if the Parent Survey had not been returned after a 2-week period past delivery.

Throughout data collection, and following methodological suggestions from Marshall and Rossman (1989, as cited in Carr, 1994), immediate data

transcription was conducted in order to keep fresh subtleties that may have been encountered during the interview and that could have been subject to fading had longer time elapsed between data collection, transcription, and preliminary data analysis.

Two hierarchical multiple regression models were built as complementary tools in better understanding the experience of parenting a child with disabilities by diverse cultural groups. Many statisticians have suggested various “rules of thumb” for determination of case-predictor ratios (e.g., 5:1, 10:1, 20:1), and thus, estimation of the sample size when building the multiple regression model that better fits a study (Harris, 1975; Tabachnick & Fidell, 1989 both as cited in Green, 1991, Stevens, 2002), others have consistently claimed the need for considering the power of the study as critical criterion for sample size determination (Algina & Olejnik, 2003). The models in the present study had 3 (Latino group) and 2 (European American group) predictors, and 38 and 32 individuals on each group, respectively. Even though this study could have built one cross-cultural model utilizing all 70 participants, and be methodologically safer, the goal of this study was to explore the culture-specific experience of parenting a child with disabilities; these two multiple regression models contributed with that objective, they were not utilized for the purpose of testing a research hypothesis.

It is due to this study’s objective that the liberty of building both models with smaller samples was taken, primarily due to the scarcity of research in the cross cultural area of disabilities and stress, and also because there are virtually

no studies with immigrant populations conducted in the United States regarding this topic.

Data Analysis

The Statistical Packet for the Social Sciences (version 11.5 for Windows) was utilized to record the data and to perform the statistical analyses. Except for the open-ended question (i.e., item 66a), all participants' responses were coded with values that could be processed by the software (Fowler, 1993). The first step in data analysis was to check the assumptions and requirements for the utilization of parametric statistical procedures (i.e., normality, homogeneity of variance, collinearity, linearity, homoscedasticity). With this purpose, histograms and error bars were produced and tests such as Kolmogorov-Smirnov, Shapiro-Wilk, Levene, and Durbin-Watson were run. Descriptive statistics such as means, modes, ranges, and standard deviations were calculated. The inferential statistics utilized to respond the research questions and test the research hypothesis were as follows:

Research Question # 1 - What are the preliminary coefficients of reliability and validity of the Spanish Questionnaire on Resources and Stress? The inferential statistic utilized was Pearson-product moment correlation.

Research Question # 2 - What relationships exist among stress, culture, disabilities, and demographic variables in a sample of immigrant Latino and European American parents of young children with disabilities? The inferential statistics utilized were Pearson-product moment correlation, Spearman's Rho correlation, Analysis of Variance (ANOVA), and Hierarchical multiple regression.

The latter was used to explore the specific influence that literature-based predictor variables had on the outcome variable stress and to identify the best fit predictive model for each cultural group.

Null Hypothesis - There are no differences in the levels of stress between Latino and European American parents of children with disabilities. The inferential statistic utilized was t-Test for independent samples. The alpha level was established at .05 for all inferential statistics and for multiple comparisons Bonferroni's correction established the alpha level at .004.

Data collected from the open ended question were subjected to a basic content analysis (Weber, 1990). All data were transcribed to a Microsoft Word document and key themes emerging from the data were coded. Themes were established by groups of words with similar meaning and were exhaustive and mutually exclusive, that is, content from one theme was not present in other. The units for analysis were phrases or whole sentences, but not entire paragraphs. This basic content analysis was not grounded on any theory; it was primarily a raw exploration of participants' comments about their experiences in raising a child with disabilities. The main criteria were, a) to identify the most commonly referred categories that would describe the entire group of participants cross-culturally and b) to identify those categories that would describe, and provide insight about, the culture-specific experience of parenting a child with disabilities.

Conclusion

This chapter presented detailed information regarding the research method employed in this study. Particular emphasis was placed on the study's

design, setting, participants, instrumentation, procedures for the preliminary validation of the short Spanish QRS, main study, and data analysis. Qualitative data were utilized with the purpose of corroborating results from the quantitative analyses.

CHAPTER IV

RESULTS

Introduction

This study had two purposes. The main purpose was to explore the relationship among stress, disabilities, and culture in a group of primarily undocumented immigrant Latino and European American parents of young children with disabilities and the impact that various demographic variables had on this relationship. The second purpose was to conduct preliminary validation of a Spanish version of the Questionnaire on Resources and Stress for Families with Chronically Ill or Handicapped Members – QRS – short version (Holroyd, 1987). The non-directional research hypothesis proposed that a difference does exist between the levels of stress of Latinos and European American parents of children with disabilities.

This chapter has been divided into five parts. The first part addresses Research Question # 1: What are the preliminary coefficients of reliability and validity of the Spanish Questionnaire on Resources and Stress QRS – short version? The second part addresses Research Question # 2: What relationships exist among stress, cultural variables, and demographic variables in a sample of immigrant Latino and European American parents of young children with

disabilities? The third part addresses the null hypothesis: There are no differences in the levels of stress of immigrant Latino and European American parents of children with disabilities and it also presents the hierarchical multiple regression models for predicting stress. The fourth part provides the results of the qualitative descriptive analysis performed with the data collected during the interviews. The fifth and final part presents the conclusions. A total of one hundred three subjects ($N = 103$) participated in this study and were distributed in four different groups:

a) Field testing group composed of 15 Latinos ($N = 15$, 11 females, 4 males). The age range was 41, 24 to 65 ($M = 44$).

b) Comparison group composed of eighteen monolingual and bilingual Latinos ($N = 18$, 17 females and 1 male). All individuals in this group were parents of a child with a typical development. The age range of participants in this group was 21, 18 to 39 ($M = 29.90$ years, $SD = 6.85$).

c) Main study Latino group composed of thirty-eight monolingual and bilingual Latino parents of children with disabilities ($N = 38$, 26 females and 12 males). The age range of participants in this group was 26, 21 to 47 ($M = 35.73$, $SD = 6.54$).

d) Main study European American group composed of thirty-two monolingual European American parents of children with disabilities ($N = 32$, 23 females and 9 males). The age range of participants in this group was 28, 30 to 58 ($M = 40.34$, $SD = 6$).

Data provided from participants in groups b and c were utilized in the calculation of the coefficients of validity and reliability of the QRS in Spanish.

A total of 15 outcome variables of stress, 14 demographic predictor variables of stress and 4 cultural predictor variables of stress were analyzed in this study. These are presented on Tables 4.1, 4.2, and 4.3, respectively.

Table 4.1

Outcome Variables of Stress

Scale I Dependency and management	Scale IX Financial stress
Scale II Cognitive impairment	Scale X Preference for
Scale III Limits on family opportunities	institutionalization
Scale IV Life span care	Scale XI Personal burden for
Scale V Family disharmony	respondent
Scale VI Lack of personal reward	
Scale VII Terminal illness stress	Personal stress
Scale VIII Physical limitations	Family stress
Total stress	Index case stress

Table 4.2

Demographic Predictor Variables of Stress

Age	Level of education	Health status	Age of the child
Gender	Family income	Body Mass Index	Diagnosis
Occupation	Marital status	Gender of the child	
Work hours	Life satisfaction	Appraisal of child's development	

Table 4.3

Cultural Predictor Variables of Stress

Cultural identification with own culture	Country of origin
Cultural identification with other culture	Number of years living in the US

Research Question # 1: What are the preliminary coefficients of reliability and validity of the Spanish Questionnaire on Resources and Stress?

The first step in answering this research question about reliability and validity of the Spanish version of the QRS was to explore the data collected from all 18 Latino parents from the comparison group and the 38 Latino parents of children with disabilities with the purpose of determining whether the data met the assumptions for the usage of parametric statistical procedures (Field, 2004). Data exploration consisted basically of the determination of normality of the distribution on stress. Since it was expected that the data were obtained from a normally distributed population, histograms were plotted for three sets of data in order to have a first look at this normality assumption. The three sets of data

were: a) Spanish QRS - odd items, b) Spanish QRS even items, and c) Spanish QRS all items. The set of even items and the set of odd items were used as alternate forms of the QRS with the purpose of calculating the coefficient of reliability.

Figure 4.1 illustrates the distribution of stress for odd and even items of the QRS in Spanish. It can be observed that responses on odd items have a multimodal distribution and are slightly positively skewed (.40). Even items are slightly positively skewed (.51) and fairly normally distributed. Figure 4.2 illustrates a positively skewed (.41) normal distribution of stress for the entire group on all items of the Spanish QRS.

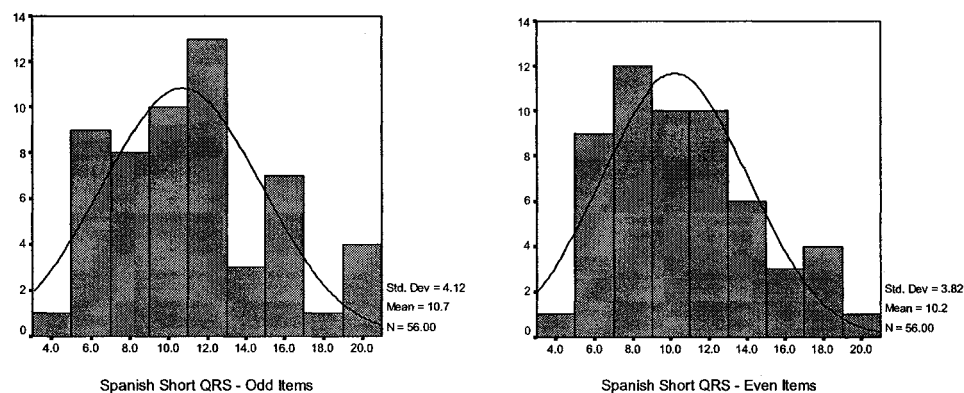


Figure 4.1 - Distribution of Stress from Odd and Even Items on the QRS in Spanish

Kolmogorov-Smirnov and Shapiro-Wilk normality tests were utilized to evaluate the distribution of stress on these three groups. Results showed that the assumption of normality for all groups was tenable, that is, the distribution for each one of the three groups (e.g., odd) in both tests did not differ significantly

from a normally distributed set of scores. Values for both tests on all three groups are shown in Table 4.4.

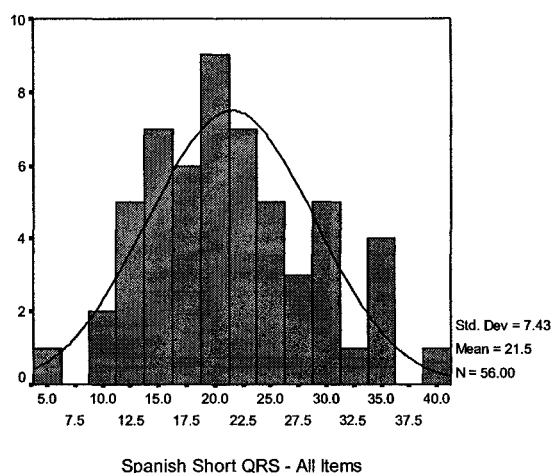


Figure 4.2 – Distribution of Stress on all Items of the QRS in Spanish
Table 4.4

Normality Tests for Preliminary Validation of the Spanish QRS

Group	Kolmogorov-Smirnov			Shapiro-Wilk		
	Statistic	df	sig	Statistic	df	sig
Odd Items	.113	56	.70	.962	56	.078
Even Items	.113	56	.70	.964	56	.094
All Items	.115	56	.62	.974	56	.263

Determination of the Spanish QRS Coefficient of Reliability

Eighteen Latino parents of children with a typical development and 38 parents of children with disabilities responded the QRS in Spanish. The split-half procedure for determination of internal consistency was utilized. This procedure required a single administration and determined the degree to which items in the QRS in Spanish correlate to each other, reflecting whether all items of the

instrument were consistently measuring stress. The QRS 66 items were divided in two: odd items ($M = 10.70$, $SD = 4.12$) and even items ($M = 10.23$, $SD = 3.82$). These two halves were treated as alternate forms of the QRS in Spanish and the Pearson product-moment correlation coefficient was calculated in order to measure the linear relationship between both halves. The coefficient of reliability was .75 ($p < .01$). A coefficient of reliability of .75 indicates that 56% of a respondent's score is true score variance while 44% is due to error of measurement. Figure 4.3 illustrates the scatterplot for this coefficient. Table 4.5 shows the coefficients of reliability for each one of the 11 scales of the QRS in Spanish.

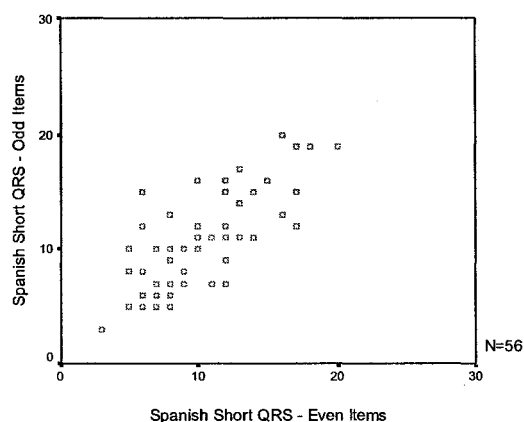


Figure 4.3 - Correlation between Level of Stress with Even Items and Level of Stress with Odd Items of the QRS in Spanish.

Determination of the Spanish QRS Coefficient of Validity

The study attempted at calculating the coefficient of criterion validity, and for this purpose the QRS in English was utilized as criterion. The low incidence of bilingual Latino participants made it difficult to produce a larger group for this validation purpose. Nine Latino parents of children with a typical development

and three parents of children with disabilities ($N = 12$) responded the QRS in English two weeks after responding the QRS in Spanish. Performances of these twelve individuals on both instruments were then correlated. Performance on the QRS in Spanish produced a stress mean level of $M = 21.25$, $SD = 6.36$, while performance on the QRS in English produced a stress mean level of $M = 19.42$, $SD = 7.76$. Pearson product-moment correlation was utilized; Figure 4.4 illustrates the scatterplot for this correlation. The coefficient of criterion validity for the Spanish QRS was estimated to be .90 ($p < .01$). Table 4.5 shows the coefficients of validity for each one of the eleven scales of the QRS in Spanish.

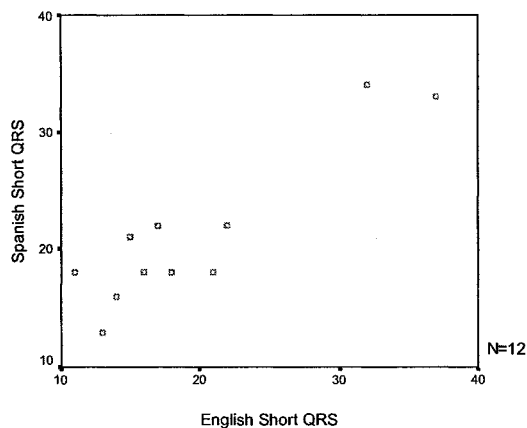


Figure 4.4 - Correlation between the Scores from the QRS in Spanish and in English

In summary, the preliminarily calculated coefficients of reliability and validity provided enough leverage to ensure that the QRS in Spanish was conceptually an equivalent version of the original Questionnaire on Resources and Stress. Statistically, levels of reliability for each one of the eleven scales seemed to have been affected by the level of variability of scores among participants (Anastasi, 1968). The coefficient of reliability for the entire translated

instrument, the coefficient of validity, as well as levels of validity for each one of the eleven scales provided confirmation that the instrument could be utilized for data collection purposes in this correlational study.

Table 4.5

Coefficients of Validity and Reliability of the scales of the QRS in Spanish

Scale	Suarez-Sousa (2006)		Holroyd (1987) ¹
	r_r	r_v	r_r
Scale I	---	.584*	.72
Scale II	.56**	.902**	.80
Scale III	---	.810*	.64
Scale IV	.66**	.923**	.70
Scale V	.50**	.902**	.60
Scale VI	---	.956**	-.23
Scale VII	---	.960**	.58
Scale VIII	.79**	.938**	.65
Scale IX	.34*	.620*	.68
Scale X	---	.734*	.40
Scale XI	.42**	.828*	.46
Composite	.75	.90	.85

* $p < .05$

** $p < .001$

--- Not statistically significant

¹ Coefficients of validity for the 11 scales were not available

Field Testing

In total, fifteen individuals participated in field testing the QRS in Spanish ($N_{\text{male}} = 4$, $N_{\text{female}} = 11$). The mean age was 44. The primary country of origin was Mexico and their professions as well as occupations broadly varied (e.g., homemaker, student, physician). Nevertheless, none of those respondents with a professional degree were working in their fields of expertise. For instance, a physician and a biologist were both working in a restaurant as waitresses. Only 20% of the respondents were bilingual and 13 of them had children. No data were collected regarding immigration status.

In all cases respondents showed familiarity with the construct of stress and provided examples of its meaning as well as of its usage (e.g., “*es estresante vivir en este país y no poder hablar inglés*” [It is stressing to live in this country and not being able to speak English]). Nevertheless, the meaning given to the construct of *estrés* was clearly pretty slack. In some of the cases it was used to represent situations embodying clear threats or challenges to the individual’s wellbeing; nevertheless, in most cases the construct was used primarily to represent any situation in where the individuals wanted to describe a general state of anxiety. The True/False format did not deter the respondent’s ability in figuring out how to respond to each one of the items; it was clear that all respondents had been exposed to this type of test format and knew how to navigate the instrument.

Item comprehension was demonstrated through the use of retrospective verbal protocols (i.e., retrospective thinkalouds). Participants were asked to

explain the meaning of two previously targeted items, which had been marked in advance on the document. In this way, 44% ($n = 30$) of the total items of the QRS in Spanish were subjected to this procedure. In 100% of the cases respondents were able to produce retrospective verbal protocols that matched the originals in terms of their semantics and none of the selected items seemed to pose any social threats to the respondents; which meant that in all cases, participants were willing to respond with the truth without feeling they could be socially criticized for providing either a True or False answer to some of the items (e.g., "It bothers me that _____ will always be this way"). In general, the field testing of the QRS in Spanish helped in determining that the inner structure of the original QRS was preserved and well represented in the translated version. Additionally, the activity served the purpose of making certain that standard Spanish was utilized and individuals from different Latin Americana countries would equally understand the content.

Research Question # 2: What relationships exist among stress, culture, disabilities, and demographic variables in a sample of immigrant Latino and European American parents of young children with disabilities?

A preliminary step in answering this research question was to explore the data collected from all 38 Latino and 32 European-American parents of children with disabilities; this consisted basically on determining the level of normality of the distribution for the variable stress by using visual analysis with the help of histograms for the following three groups: a) Latino parents of children with disabilities, b) European American parents of children with disabilities, and c)

both groups combined. Figure 4.5 shows the distribution of stress for European and Latino parents of children with disabilities separately. Stress among European American parents presents a fairly normal distribution (left); while stress among Latinos presents a more multimodal distribution. Figure 4.6 shows the distribution of stress for both groups combined. In this case, a fairly normal distribution is observed.

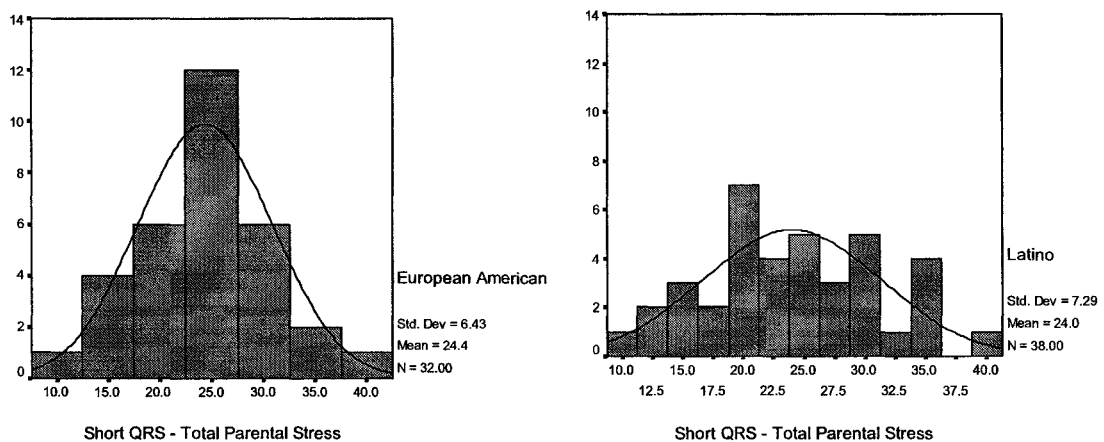


Figure 4.5 - Distribution of Stress for European American (left) and Latino Parents of Children with Disabilities.

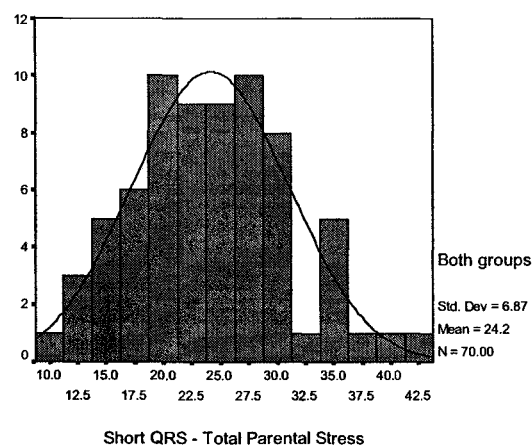


Figure 4.6 - Distribution of Stress in a combined group composed by European American and Latino Parents of Children with Disabilities

Additionally, both Kolmogorov-Smirnov and Shapiro-Wilk normality tests were utilized to evaluate the distribution of stress on these three groups, neither test produced levels that were statistically significant. Results showed that the assumption of normality for all groups was tenable. Values for both tests on the three groups are shown in Table 4.6.

Table 4.6

Normality Tests for Main Study

Group	Kolmogorov-Smirnov			Shapiro-Wilk		
	Statistic	df	sig	Statistic	df	sig
Latino	.080	38	.20	.974	38	.522
European American	.111	32	.20	.962	32	.320
Both groups	.081	70	.20	.983	70	.445

Exploration of associations between stress and demographic predictor variables

Data were analyzed through descriptive and inferential statistics. Mean, standard deviation, and proportion values for all demographic predictor variables are presented in Appendix D – Table 1. This sample was composed of a total of 70 individuals, 38 Latinos (12 males, 26 females) and 32 European Americans (9 males, 23 females). European Americans in general were older ($M = 40.34$, $SD = 6.03$) than their Latino counterparts ($M = 35.73$, $SD = 6.54$). Figure 4.7 illustrates the age distribution.

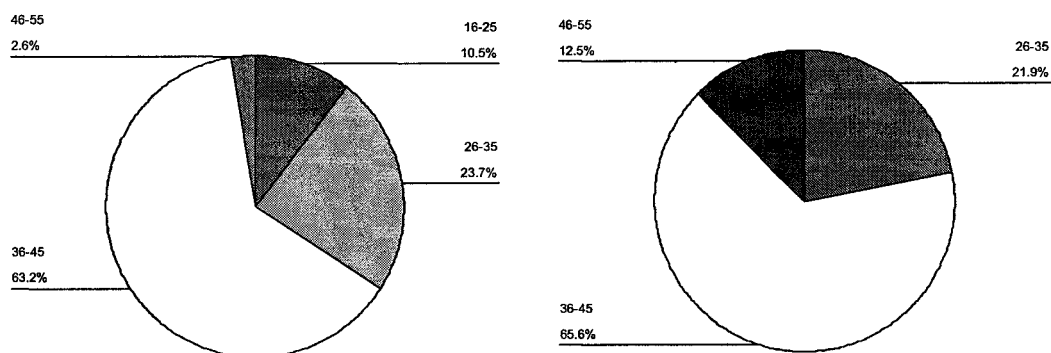


Figure 4.7 – Age Distribution for Latinos (Left) and European Americans

In both cases the majority of participants was married and reported being fairly satisfied with the current status of their lives. Approximate 60% of the total sample was parenting a boy. The three most prevalent disabilities were, 1) mental retardation: Latinos: 45% and European Americans: 36%, 2) Pervasive Developmental Disorders – PDD: Latinos: 8% and European Americans: 47%, and finally, 3) Orthopedic Impairments: Latinos: 34% and European Americans: 6%. Figure 4.8 illustrates the distribution of disabilities for the entire group. Latino immigrants were either documented (18%) or undocumented (80%), or did not report their immigration status (2%).

Latinos and European Americans differed in terms of their levels of education and income, for both of which European Americans proportionally surpassed the Latino participants. European Americans reported having more college and graduate levels of education and declared a combined household income of \$50,000/year or more, while Latinos reported accomplishing

predominantly primary and secondary levels of education and a combined household income of \$50,000/year or less.

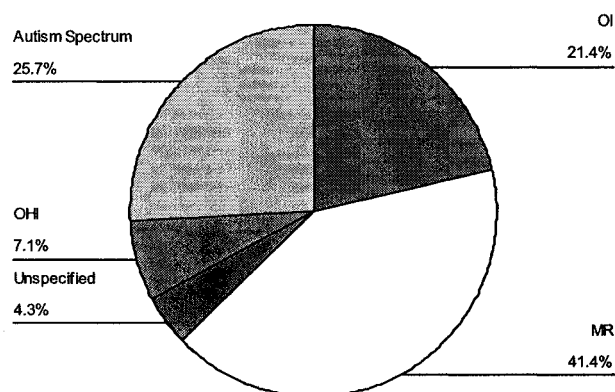


Figure 4.8 – Distribution of Disabilities

Exploration with all participants

In order to get a general, cross cultural view of the experience of parenting a child with disabilities data from all participants was analyzed. Stress was found to be strongly correlated to few demographic predictor variables. The strongest of all predictors was the parents' appraisal of child development, $r = -.609$, $p < .000$ (two-tailed); parents who appraised their child's development as closer to the expected for the child's age reported lower levels of stress, this correlation is illustrated in Figure 4.9. Since this is a variable composed by 5 developmental areas (See Appendix D – Table 1) it was further decomposed for analysis. All five developmental domains were found to be moderately correlated to stress; in hierarchical order of magnitude, the correlations were: a) cognitive domain, $r = -$

.559, b) motor domain, $r = -.540$, c) adaptive domain, $r = -.515$, d) communication domain $r = -.433$, and finally, e) social domain, $r = -.362$. All these correlations were significant at the .01 level (two-tailed).

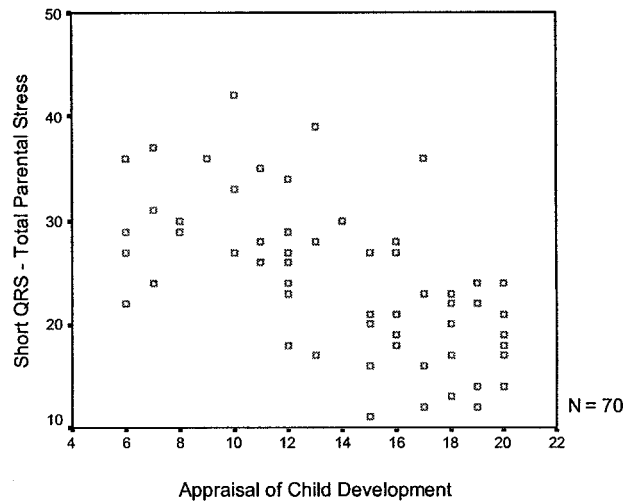


Figure 4.9 – Correlation between Total Stress and Respondent's Level of Appraisal of Child Development

Appraisal of life satisfaction, $r_s = -.413$, $p < .001$ (two-tailed), was the second most important predictor variable of stress; parents who stated feeling more satisfied with the current status of their lives experienced lower levels of stress. Gender was weakly correlated to the total level of stress, $r_s = -.238$, $p < .047$ (two-tailed); nevertheless, this correlation suggested that mothers reported being more stressed than fathers.

Further examination required decomposing the variable stress into its three categories of personal, family, and index case stress (See Table 4.1). Personal stress was correlated with two predictor variables, the first one was the parents' appraisal of child's development ($r = -.418$, $p < .001$) followed by the

child's age, ($r = .314, p < .01$) indicating that the older the child the higher the level of personal stress. Family stress was correlated with 4 predictor variables, the first one was the parents' Body Mass Index was ($r = .318, p < .05$) suggesting that the heavier the parent the more family stress that is reported; the second variable was the parents' age ($r = -.281, p < .05$), in this case older parents reported lower levels of stress; the third variable was the appraisal of child's development with a relatively weak correlation ($r = -.253, p < .05$); the fourth, and last variable was the child's gender ($r_s = -.244, p < .05$) and here parents reported higher levels of family stress when raising a girl with disabilities ($M = 6.38^1, SD = 2.76$). Finally, two predictor variables were associated with index case stress; as expected, the first one was appraisal of child's development which obtained the highest level of correlation for this category of stress ($r = -.683, p < .001$), with all five developmental domains playing equally significant roles in predicting index case stress; the second variable was the child's gender ($r_s = -.397, p < .01$), showing again that parenting a girl with disabilities was associated to more stress.

Exploration with Latinos and European Americans separately

In order to explore the role played by the culture of the parents, data from Latinos and European Americans were analyzed separately. Level of stress for these two cultural groups became associated to different variables. This was the case, for instance, of the variable level of education; a first order partial correlation showed that Latino women reported higher levels of stress ($p_r = .338, p < .05$). Stress among Latino parents was not associated at all with the child's

¹ Family stress is composed of 3 scales, this can produce a total score ranging from 0 to 18.

emotional development while, a similar neutral effect was with child's adaptive development among European Americans; in both cultural groups, the remaining four areas of child's development were indeed moderately correlated to stress.

The following analyses looked at each one of the three categories of stress. Personal stress among Latinos was correlated to appraisal of all child's developmental areas with the exception of the child's social development (adaptive domain: $r = -.354$, $p < .01$; communication domain: $r = -.384$, $p < .05$; motor domain: $r = -.387$, $p < .05$; cognitive domain: $r = -.532$, $p < .01$; two-tailed in all cases). Interestingly, personal stress in European American parents was not at all associated to appraisal of child's development, it was associated only with appraisal of life satisfaction ($r_s = -.514$, $p = .01$ (two-tailed), this indicated that higher levels of life satisfaction were associated with lower levels of personal stress for this cultural group. Family stress among Latinos was correlated with four predictor variables (See Table 4.7) among which the most important was life satisfaction ($r = -.472$, $p < .01$), and it was also correlated with only two areas of the child's development: motor ($r = -.367$, $p < .05$) and adaptive ($r = -.416$, $p < .05$); while in the case of European Americans, family stress was correlated exclusively with appraisal of the child's cognitive development ($r = -.356$, $p < .05$). In the case of index case stress, this category of stress was exclusively correlated with appraisal of child's development among Latino parents (See Table 4.8), this predictor variable was also relevant for European American parents but it was not the only one, life satisfaction ($r = -.390$, $p < .05$) and the

child's age ($r = -.393$, $p < .05$) played moderate roles in predicting index case stress among parents from this cultural group.

Table 4.7

Correlation values between Family Stress and Demographic Predictor Variables of Stress analyzed by Culture

Variable	Latino r/r_s	European American r
Age	-.318*	--
BMI	.421*	--
Income	-.352 _s *	--
Life satisfaction	-.472 _s **	--
Adaptive development	-.416*	--
Motor development	-.367*	--
Cognitive development	--	-.356

* $p < .05$ ** $p < .01$

_s Spearman's Rho

In summary, of all explored demographic predictor variables, few of them were found to be playing a role in the experience of stress among individuals raising a child with disabilities. A preponderant association was observed between stress and the parents' appraisal of child development (with the inclusion and exclusion of the five developmental domains depending on the stress category being analyzed), age and gender of the child, as well as appraisal of life satisfaction. Less relevant roles in the experience of stress associated with parenting a child with disabilities were played by the age of the parent, the BMI, and the family income.

Table 4.8

Correlation values between Index Case Stress and Demographic Predictor

Variables of Stress analyzed by Culture

Variable	Latino r/r_s	European American r/r_s
Life satisfaction	--	-.390 _s *
Appraisal of child's development	-.749**	-.534**
Adaptive	-.749**	-.392*
Communication	-.532**	--
Social	-.396*	-.520**
Motor	-.754**	-.416*
Cognitive	-.540**	-.492**
Age of the child	--	.393*

* $p < .05$ ** $p < .01$ _s Spearman's Rho*Exploration of associations between stress and cultural predictor variables*

Data were analyzed through descriptive and inferential statistics. Mean, standard deviation, and proportion values for all cultural predictor variables are presented in Appendix D – Table 2. Results from the analyses indicated that cultural identification with the Latino culture (i.e., cultural practices, feelings of respect and membership) was similarly strong between Latino males ($M = 22.7$) and Latino females ($M = 21.48$). On average, Latinos reported living in the US little less than a decade and Mexico constituted the primary source of immigration in this sample (74%) as it is illustrated in Figure 4.10.

Noteworthy is that a statistically significant difference was observed between European American males and females regarding cultural identification with their own culture, males reported a weaker identification ($M = 16$) than females ($M = 20.74$), and by extension, weaker than Latino males and females with respect to own culture.

When examining data collected from Latinos and European Americans separately, Pearson product-moment correlations and Spearman's Rho correlations were utilized to identify cultural-specific predictor variables associated with stress. The experience of global stress, personal stress, and index case stress among Latinos were all positively correlated to cultural identification with the host culture, specifically with the level of incorporation of its traditions and life practices—ciAng1 ($r = .433, p < .05$; $r = .501, p < .05$; $r = .372, p < .05$, respectively). These results surprisingly indicate that immigrant Latinos report lower levels of stress when they happen to incorporate and practice in lesser degrees mainstream American beliefs and life practices. Family stress, on the other hand, was found to be negatively correlated with the feelings of capability, respect, and competence in the Latino culture—ciLat3 ($r = -.379, p < .05$) and to the number of years the respondent had been living in the US ($r = -.509, p < .001$), which is illustrated in Figure 4.10. As expected, these results showed that the Latino community may be functioning as a social coping resource to reduce the level of family stress.

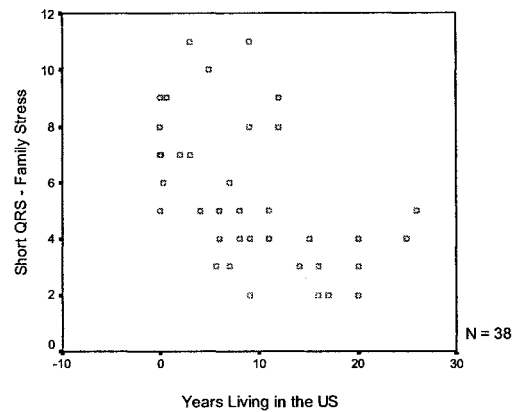


Figure 4.10 – Correlation between Level of Family Stress and Number of Years Living in the US among Latinos

Among European Americans the only cultural predictor variable that had an association with their experience of stress was the level of active involvement in culture-specific activities and traditions from their own culture—*ciAng2* ($r = -.396, p < .05$), which correlated to the level of index case stress. This result indicated that European American parents of children with disabilities reported lower levels of preoccupation about their children's condition and capability for independent living when parents were actively involved in activities that were conceptualized as being properly American (e.g., charitable work).

In summary, of all explored cultural predictor variables in the preceding analyses, few of them have been found to have an important role in the experience of stress primarily among Latino individuals raising a child with disabilities. This is the case of parents' cultural identification with the Anglo culture Levels 1 and 2, cultural identification with the Latino culture, Level 3, and the number of years spent in the US (for Latinos only); which is further analyzed later in this chapter.

Null Hypothesis: There are no statistically significant differences in the levels of stress between Latino and European American parents of children with disabilities.

Data were analyzed through descriptive and inferential statistics. Mean and standard deviation values for all stress outcome variables are presented in Appendix D – Table 3. The first step in testing this study's null hypothesis was to conduct the Levene test which confirmed that both groups had equal variances, $F(68) = .906, p = .345$. Visually, an error bar gave an indication that there was no difference between both cultural groups regarding the experience of stress (Figure 4.11) and a t-Test confirmed that there was no statistically significant difference between the mean levels on stress for Latino and European American parents of children with disabilities ($M_L = 23.97, SD_L = 7.30; M_{EA} = 24.38, SD_{EA} = 6.44$, respectively; $t = -.242, p > .81$). The null hypothesis was then accepted.

Further comparisons indicated no statistically significant difference existed between Latinos and European Americans regarding their levels personal, family, or index case stress. Similarly, comparisons were conducted for each one of the 11 scales of the QRS; utilizing the Bonferroni correction for multiple comparisons which established the level of significance for these comparisons was established at $p = .004$. The only scale that reached statistical significance was scale X, $t(68) = 3.54, p < .001$, in which Latinos reported higher level of stress in regard to preference for institutional care. Figures 4.12 and 4.13 illustrate the cross-cultural stress profile and the comparison between the stress profiles of the Latino and European American.

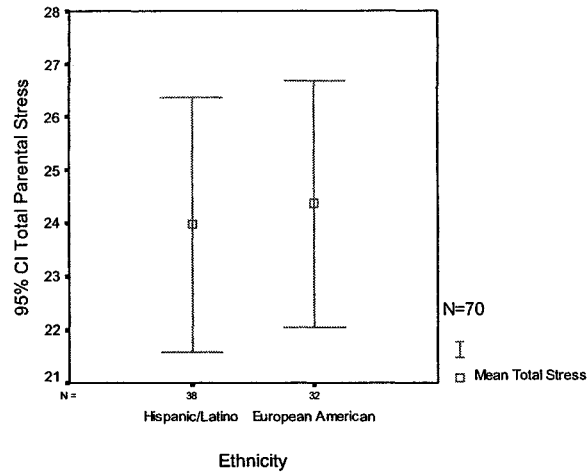


Figure 4.11 – Comparison of Mean Levels of Stress by Culture

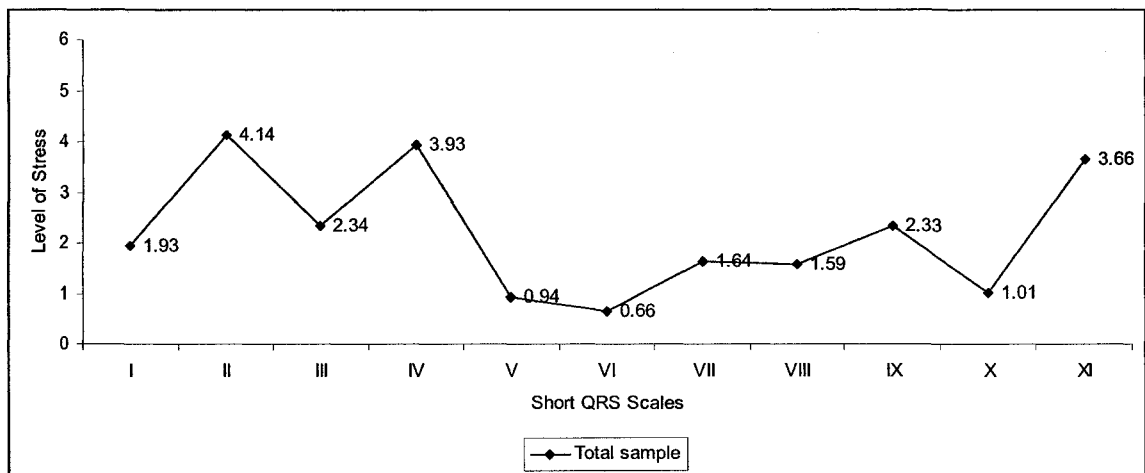


Figure 4.12 – Combined Stress Profile of Latinos and European American Parents of Children with Disabilities

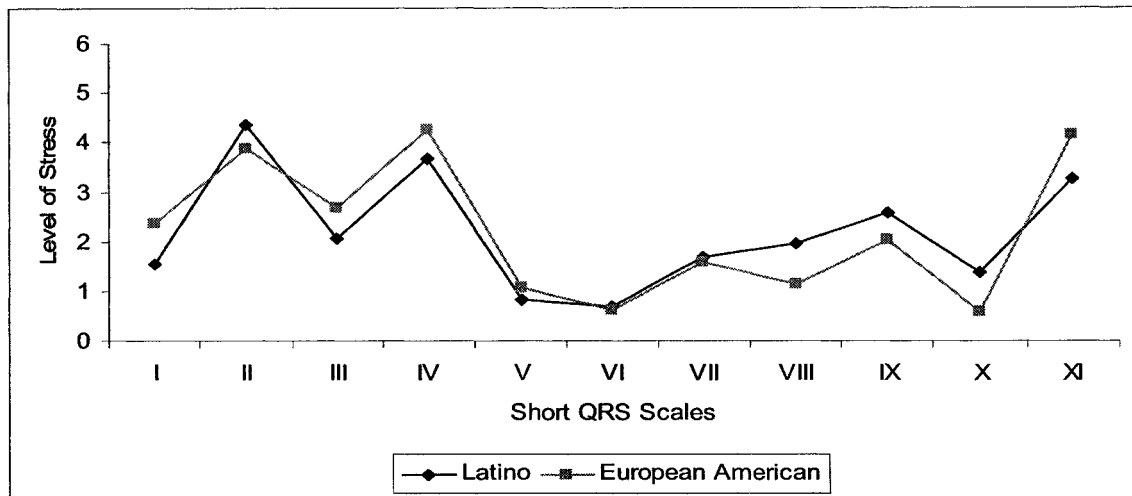


Figure 4.13 – Comparison of Stress Profiles between Latinos and European American Parents of Children with Disabilities

Stress comparisons between men and women showed that the only statistically significant difference was in the level of personal burden (i.e., scale XI); across cultures, fathers ($M = 2.43$, $SD = 1.03$) reported lower levels of personal burden than mothers ($M = 4.18$, $SD = 1.42$), $t(68) = 5.10$, $p < .001$. Figure 4.14 illustrates this difference. The differences between Latino males and females ($M = 2.00$, $SD = 0.85$ and $M = 3.81$, $SD = 1.58$, respectively; $t(36) = 3.71$, $p < .01$) and European Americans males and females ($M = 3.00$, $SD = 1.00$ and $M = 4.61$, $SD = 1.12$, respectively; $t(30) = 3.76$, $p < .01$) were remarkable .

There was no statistically significant difference in the total levels of stress between documented ($M = 26.14$) and undocumented ($M = 23.48$) Latino immigrant parents of children with disabilities, nor on each one of the eleven scales of the QRS.

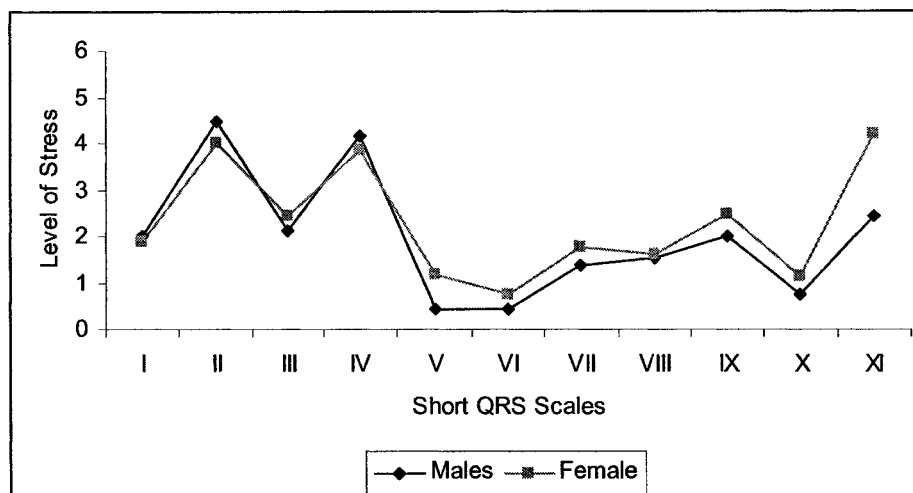


Figure 4.14 – Comparison of Stress Profiles between Male and Female Parents of Children with Disabilities

Other statistically significant differences were observed within the Latino group in where Latino females ($M = 11.42$, $SD = 3.40$) reported higher level of personal stress than did their male counterparts ($M = 8.92$, $SD = 3.40$), $t(36) = 2.12$, $p < .05$), and between Latino and European American males on scale X (i.e., preference for institutionalization), $t(19) = 3.34$, $p < .01$ in where Latino males reported a level of stress three times higher than their European American counterparts. Analysis of variance (ANOVA) gave no indication of differences in the levels of stress among Latinos coming from either country represented in the sample and among parents of children with different types of disabilities. There was also no difference in the levels of stress between Latino monolinguals and Latino bilinguals and there was no indication that Latino parents of a U.S. citizen child with disabilities reported higher levels of stress than Latino parents of an immigrant child with disabilities.

The sample in the present study included 19 couples, ($N = 10$ Latinos, $N = 9$ European Americans). Utilizing Bonferroni correction for multiple comparisons, examinations were conducted on all 15 outcome variables of stress ($p = .004$). No differences between husbands and wives were found, with the only exception of Scale XI in where, as it had been described in the preceding section, wives reported higher levels of personal burden stress than did their spouses ($t(35) = .571, p < .001$). Levene's test confirmed the equality of variances for both groups on this measure ($F = .428, p = .517$). Finally, comparisons with parents of children with a typical development were conducted. Parents of children with a typical development reported statistically significant lower levels of stress ($t(89) = -5.04, p < .001$) than parents of a child with disabilities. Appendix D – Table 4 shows mean and standard deviation values for the comparison group on each one of the outcome variables of stress. Figure 4.15 illustrates how these two groups compared on the main categories of stress.

In summary, both cultural groups reported equivalent levels regarding the global outcome of stress, as well as on each one of its three components (i.e., personal, family, index case). The only divergence between cultures was found on scale X, in which Latino males reported a higher stress level in regards to their preference for institutional care than European American males. Gender was associated with a couple of differences. First, mothers across cultures reported higher levels of personal burden due to the care of their children with disabilities than did fathers. Second, Latino mothers reported higher levels of personal stress than did their spouses. Parents of children with a typical

development reported statistically significant lower levels of parental, personal, family, and index case stress than did parents of children with disabilities. No other statistically significant differences were attained.

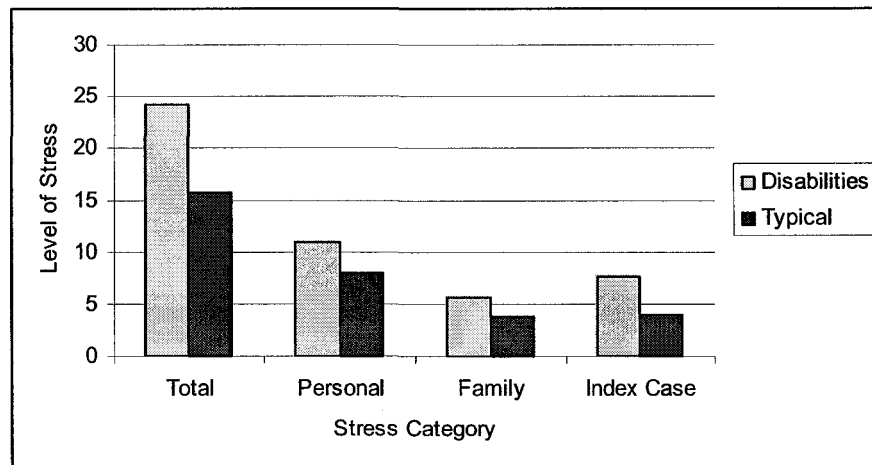


Figure 4.15 - Comparison between Parents of Children with Disabilities and Parents of Children with a Typical Development on four selected Outcome Variables of Stress

Hierarchical Multiple Regression Model of stress

Two models seemed to best fit each one of the two cultural groups in this study. For Latinos, the combined effects of one predictor demographic variable and 2 predictor cultural variables explained the major proportion of stress (66%). These variables were, in this specific order, a) Appraisal of child's motor development, b) Cultural identification with host culture – Level 1, and c), Cultural identification with own culture. For European Americans, the combined effects of two demographic predictor variables explained the major proportion of stress (67%). These variables were, in this specific order, a) Appraisal of child's

cognitive development and b) Life satisfaction. The following section will assess each one of these hierarchical multiple regression models in terms of their diagnostic and generalization capabilities as well as their fitness to this study's data.

Hierarchical Multiple Regression Model for Latinos

Table 4.9 summarizes the hierarchical multiple regression model for Latino parents.

Table 4.9

Summary of Hierarchical Multiple Regression Model for Latino Parents of Children with Disabilities

Model R	R ²	Adjusted R ²	SEE	Change Statistics			
				R2 change	F change	p	DW
1	.651 ^a	.424	.404	5.975	.424	21.351	.000
2	.741 ^b	.549	.517	5.379	.125	7.787	.009
3	.809 ^c	.655	.617	4.791	.106	8.286	.008
							1.364

a Predictor: Appraisal of motor development

b Predictors: Appraisal of motor development, Cultural Identification with European American culture - Level 1 (CI Anglo L1)

c Predictors: Appraisal of motor development, CI Anglo L1, Cultural Identification with Latino Culture (CI Lat)

The first look at the model gives indication of lack of multicollinearity among the 3 predictor variables ($R < .9$), in where the highest correlation was between appraisal of motor development and level of cultural identification with the Latino culture ($R = -.177$). The Latino model indicates that the predictor variable appraisal of motor development accounted for 42% of the variation in

stress. However, when the predictor variable cultural identification with the European American culture - Level 1 (Anglo L1) was added (model 2) this value increased to 55% of the variance on stress. Finally, when a third predictor variable was added, that is, the level of cultural identification with the Latino culture (CI Lat) (model 3), the R square value increased to .655 indicating that the combination of these 3 predictor variables was able to explain 66% of the variance observed on stress. Progressively, the inclusion of each predictor has explained a larger amount of the variation in stress among Latino parents of children with disabilities. Change statistics provided additional indication of the difference made by adding new predictors to the model. The adjusted R square values are very close to the R square values giving an indication that this model can be generalized. Additionally, the Durbin-Watson test reached a value of 1.4 giving an indication that the assumption of independence of errors (i.e., no correlation of residuals) was tenable for the sample size and a model composed of 3 predictor variables. Analyses of variance showed the significance in the predictability power of model 1, $F(1,29)= 21.35, p < .001$; model 2, $F(2,28)= 17.07, p < .001$; and model 3, $F(3,27)= 17.10, p < .001$. Similarly, beta values provided an estimate of the individual contribution of each predictor to the model; that is, gave an indication of how much each predictor had the capability of affecting stress given that all other predictors are held constant. These are shown in Table 4.10.

From Table 4.10, t values indicated that β values were significantly different from zero (i.e., no contribution); that is, confirming the individual

contribution of each predictor variable to the model. In this case, appraisal of child's motor development is the one playing the greatest contribution in the model, while the other two variables had a moderate impact.

Table 4.10

Beta values of the Hierarchical Multiple Regression Model of Stress for Latino Parents of Children with Disabilities

Predictor	β	Std. Error	Std. β	t	p	<u>Collinearity statistics</u>	
						Tolerance	VIF
(Constant)	57.261	9.735		5.88	.000		
Motor	-4.77	.818	-.676	-5.83	.000	.947	1.056
CI Anglo L1	1.43	.565	.294	2.53	.017	.951	1.051
CI Lat	-1.05	.366	-.337	-2.88	.008	.934	1.070

Standardized β values indicated that CI Anglo L1 and CI Lat were virtually identical in terms of their degree of importance for the model and collinearity values confirmed that there was no collinearity within the data. Casewise diagnostics indicated that a single case had a standardized residual of 2.74, which because of being below 3.00 was not a real cause of concern for the purpose of creating undue influence on the model and need for further examination. Assumptions of linearity and homoscedasticity were met.

Hierarchical Multiple Regression Model for European Americans

The first look at the model gives indication of lack of collinearity among the 2 predictor variables ($R < .9$), in where the correlation between both is weak ($R = .221$). Table 4.11 summarizes the hierarchical multiple regression model for European American parents. The first model indicates that appraisal of child's cognitive development accounted for 37% of the variation in stress. However, when level of life satisfaction was added (model 2) this value increased to 46% of the variance on stress. The combined effect of these two predictors has explained a larger amount of the variation in stress among this cultural group. Change statistics provided additional indication of the difference made by adding one predictor to the initial model.

The adjusted R square values were relatively close to the R square values giving fairly certain indication that this model could be generalized. Additionally, the Durbin-Watson test reached a value of 1.825 indicating that the assumption of independence of errors (i.e., no correlation of residuals) was tenable for the sample size and a model composed of 2 predictor variables. Analyses of variance showed the significance in the predictability power of model 1, $F(1,29) = 17.24, p < .001$, and model 2, $F(2,28) = 11.92, p < .001$. Similarly, beta values provided an estimate of the individual contribution of each predictor to the model. These values are shown in Table 4.19. From Table 4.12, t values indicated that β values were significantly different from zero (i.e., no contribution); that is,

confirming the individual contribution of each predictor variable to the model. In this case, the two predictors shared an equal contribution in the model.

Table 4.11

Summary of hierarchical Multiple Regression Model for European American Parents of Children with Disabilities

Model	R	R ²	Adjusted R ²	SEE	Change Statistics			
					R2 change	F change	p	DW
1	.614 ^a	.373	.351	5.24	.373	17.244	.000	
2	.678 ^b	.460	.421	4.949	.087	4.509	.043	1.825

a Predictor: Appraisal of child's cognitive development
b Predictors: Appraisal of child's cognitive development, Life satisfaction

Table 4.12

Beta values of the Hierarchical Multiple Regression Model of Stress for European American Parents of Children with Disabilities

Predictor	β	Std. Error	Std. β	t	p	Collinearity statistics	
						Tolerance	VIF
(Constant)	39.519	3.742		10.56	.001		
Cognitive	-3.39	.886	-.544	-3.82	.001	.951	1.051
Satisfaction	-2.58	1.21	-.302	-2.12	.043	.951	1.051

Standardized β values indicated that no predictor had the same degree of importance for the model. All collinearity values confirmed that there was no collinearity within these data and casewise diagnostics indicated that no case was a real cause for concern either. There was a slight indication of homoscedasticity.

Considering that Latinos and European Americans differed in terms of the distribution of their children's disabilities, which may have explained the differences in the hierarchical multiple regression models, Table 4.13 provides further corroboration to the suggestion that the role played by the child's motor and cognitive development is culture specific.

Table 4.13

Correlations between Child's Disability and Appraisal of Motor and Cognitive Development

	Latino		European American	
	Cognitive	Motor	Cognitive	Motor
PDD ¹	-.990	-.990	-.401	-.246
OI ²	-.736	-.908	-.1.00	
MR ³	-.288	-.426	-.780	-.499

1 Pervasive Development Disorders

2 Orthopedic Impairments

3 Mental Retardation

It is clearly that stress reported by Latino and European Americans, across these three types of disabilities, is highly associated with appraisal of

motor development for the former and with appraisal of cognitive development for the later group.

Qualitative Data Analysis: Basic Content Analysis

The Parent Survey included the following open question: "Please, share with us in what ways (if any) your life changed since your son/daughter with disabilities was born." The following basic content data analysis (Weber, 1990) attempted at summarizing the qualitative data collected specifically through the aforementioned question as well as the supplementary qualitative data provided by participants all through the conduction of personal interviews. Due to their frequency, statements were classified into themes. These themes were arranged into two major categories that were identified and named by the author. The first theme category was named *global themes*, which contained themes that were applicable to the group in its entirety (i.e., Latinos and European Americans). These themes are considered cross-cultural and are comprised of statements produced by both cultural groups. The second theme category was named *culturalized themes*, which contained those applicable only to one, but not the other, cultural group (i.e., Latinos or European Americans, not both). These themes are considered culture-specific and are comprised of statements produced by either group exclusively. The following section will provide brief information about the constitutive themes for each one of these two theme categories.

I. Theme Category: Global themes

Only one global theme was identified: "Child as a positive impact on personal life." This theme was characterized primarily by statements that emphasized on the positive impact the child with disabilities has had on the respondent's life; that is, how the child has enriched the psychological, inner life of his parent and how the child has become a source of pride, joy, amusement, and as a source of a general sense of satisfaction with the parenting role. The following are examples of statements that belong to this theme. The translation is presented immediately after, in italics.

Examples from Latinos: "Mi hijo es una bendición," "El te hace una mejor persona," "No cambiaría a mi niña por nada," "Te abren una ventana de sentimientos que no sabías que tenías," "El me saca de mi tristeza porque es diferente a mis otros hijos...trae el bullicio, hace que me despierte," "Mi vida sin mi hijo sería muy dura," "Ahora soy fuerte y sensible" "Nos hemos adaptado a él, él es muy valioso para mi."

["My child is a blessing," "He makes you a better person," "I wouldn't change my girl for anything," "They open up in you a window of feelings you did not know you had," "He takes me away from my sadness because he is quite different from my other children...he brings the party, he wakes me up," "My life without my child would be tough," "Now I am a strong and sensitive person," "We have adapted to him, he is so precious to me."

Examples from European Americans: “Since she entered my life I have become a much better father,” “X has actually been a blessing,” “My *special* son has brought me feelings of deep joy and love that no one else could have...If I could go back in time and make him *normal* I don’t think I would. He is so special to me, and our family as a whole and makes us all better people,” “I have learned to be more patient and to find joy in the small accomplishments, I have learned to slow down and enjoy life,” “I understand what really matters in life, your health, ability to communicate, inner happiness, acceptance of others of diversity and of all people with disabilities,” “I have become a much stronger person having to fight for my child’s rights” “Overall I would say my life is better. The pace is slower and I appreciate small things that I never noticed before”

II. Theme Category: Culturalized themes

Five culturalized themes were identified. Three themes were extracted from statements made by Latino parents and 2 from the statements made by European American parents. Again, these culturalized themes are exclusive of each group and, thus, show culture-specific emphasis on certain experiences. The themes that surfaced from statements made by Latinos were virtually absent from the statements collected from European Americans and vice versa.

Latino culturalized themes seem to be a direct reflection of their experience as immigrant individuals. The themes “Negative experiences with

health professionals in the US,” “Reasons for immigration,” and “Missing home country” highlight their condition and constant reminder of being a foreign citizen or an *alien* and feelings of isolation and alienation seem to be components of this experience. The child with disabilities was somehow targeted as catalyst for immigration decisions into the US.

Latino culturalized themes

a) Negative experiences with health professionals in the US

Examples: “Y la enfermera me dice, ‘Qué no sabe? Su niño está mal mentalmente...¿Usted no se chequeaba?’” “Es que le está dando muchas tortillas’ (Dice el doctor para explicar el por qué el hijo de esta participante tenía un problema en el hígado),” “Toda su familia se va a enfermar,” “El doctor me lo dijo como si me estuviera dando la peor noticia de mi vida...mi esposo se puso muy triste, él no entendió porque no habla inglés pero supo que era algo malo por la cara del doctor,” “Había notado que la bebé no se movía mucho y le avisé al doctor, pero me dijo que no era nada de qué preocuparse,” “Una de las enfermeras le dió un manazo cuando él tenía unos meses de nacido y fue porque como todo niño le agarró unos papeles que ella había dejado en la camilla donde el bebé estaba echadito y él los arrugó...Pero eso sí, yo me le enfrenté, nadie le hace eso a ninguno de mis hijos.”

[“And the nurse said to me, “What, you did not know? Your child has a mental problem...Didn’t you go for your check ups?” “The

problem is that you are giving your child too many tortillas (Doctor explaining why her child had a liver problem),” “Your entire family is going to be sick,” “The doctor told me as if he was giving me the worst news of my life...my husband became saddened, he did not understand because he does not speak English but he knew it was something bad because of the doctor’s face,” “I had noticed that the baby was not moving much so I talked to the doctor, but he said that it was nothing to worry about” (the baby was born with Down syndrome a condition that has been associated with reduced fetal movement).

b) Reasons for immigration

Examples: “Así quisiera darle lo mejor a mi hijo no podría dárselo allá...no hay servicios gratuitos,” “En México los tratan de esconder,” “En México no es fácil conseguir terapias,” “Los niños con discapacidades están más valorados aquí que en nuestros países,” “Aquí los niños tienen derechos,” “En mi país la educación especial y las terapias son muy costosas,” “Nosotros nos vinimos aquí por ellos (dice la mamá de un par de niños con parálisis cerebral).”

[I could not give my child the best in my country...there are no free services,” “In Mexico people try to hide children with disabilities,” “In Mexico is not easy to access therapeutic services,” “Children with disabilities are not valued in our countries as they are here,” “Children

here have rights,” “In my country special education services are very expensive,” “We came to this country because of them [says the mother of two children with cerebral palsy].”

c) Missing home country

Examples: “La vida aquí es muy solitaria,” “En México podría salir a pasear con mi familia, comer en grupo en la casa con amigos, tener otros niños que visiten a X, ir de vacaciones,” “Aquí uno vive muy solo,” “En Guate tengo muchos amigos, mi familia...aquí a nadie,” “Ay si, yo extraño mucho mi país. ”

["Life here is very lonely,” “In Mexico I could be outing with my family, eating with my friends at home, having other kids coming to visit X, go on vacations,” “Here one has a very lonely life,” “In Guatemala I have lots of friends, my family...here, I have no one,” “Yes, I miss my country very much.”]

European American culturalized themes

European American culturalized themes were, “Restrictions in work/professional life” and “Restrictions in social life;” both surfaced from statements that emphasized on areas of restrain that they as individuals, as well as members of a family unit, had experienced distinctively since the birth of their children with disabilities.

d) Restrictions in work/professional life

Examples: “My life has changed in regards to my career. My plan was to go to college full time in a program that required me to be

there from 8 to 4 or 5 everyday. But since finding care for my son after school is virtually impossible I have decided to change my major. As a result of this my husband will not be able to retire after 20 years of military service as planned,” “I decided not to go to medical school because he needed me at home,” “I was in college when we realized there was a problem with our child so I took time off and never returned.”

e) Restrictions in social life

Examples: “Not being able to go to a lot of places, because the noise level from other people, she gets scared and starts crying,” “Taking my son to places is more work and I believe we don’t go as many places as I would otherwise,” “We stay home more than we did before and don’t quite have the freedom we used to,” “Another change has been a decrease in social activities with other families,” “It limits my freedom somewhat, for vacations,” “At this time we are forced to remain at home most of the time which limits our opportunity for maintaining friendships,” “I have no recreation/hobbies/fun times of my choice. All life is centered around care, school, training of X.”

Finally, parents were asked to report about any other factors that might have been also contributing to their general level of stress. Appendix D – Table 5 contains the proportion values of the most commonly mentioned factors. For European Americans it is clear that the realms of work, finances, and marriage

were the most frequently reported contributing factors to the general experience of stress. For Latinos finances, family, and work factors were the most commonly mentioned, and family was a factor described within a deficit context in which they reported missing relatives who do not live in the United States.

Conclusion

Several predictive variables were identified as being crucial for explaining the global experience of stress. Some of these were equally relevant for both cultural populations, while others were found to be culture-specific. Appendix D – Table 6 presents a summary of all results. It provides information on each research question, the statistics employed and the predictor variables that were found to be associated with the outcome variable stress as well as its three main categories (i.e., personal stress, family stress, index case stress). It also presents the results obtained in building hierarchical multiple regression models of stress as well as the global and cultural themes obtained from conducting a qualitative descriptive analysis with the collected data from open ended questions during the interviews.

CHAPTER V

SUMMARY, DISCUSSION, IMPLICATIONS, AND RECOMMENDATIONS

Introduction

The purpose of this study was twofold. First, it aimed at conducting preliminary validation of a Spanish version of the short Questionnaire on Resources and Stress for Families with Chronically Ill or Handicapped Members – QRS (Holroyd, 1987). Second, this study aimed at exploring the relationships among stress, disabilities, and culture and at examining the role played by various predictor variables in a group of primarily undocumented Latino immigrants and European American parents of children with disabilities.

The construct of stress was defined as the “particular relationship between the person and the environment that is appraised by the person as taxing or exceeding his or her resources and endangering his or her well-being” (Lazarus & Folkman, 1984, p.19). All predictor variables were organized into two groups: demographic predictor variables of stress (i.e., age, gender, marital status, occupation, work hours, health status, health, life satisfaction, family income, level of education, age of the child, gender of the child, diagnosis, appraisal of child development) and cultural predictor variables of stress (i.e., cultural

identification with own culture, cultural identification with host culture, country of origin, and number of years living in the United States).

In total, 103 individuals participated in this study, thirty two were European American and seventy one were Hispanic/Latino. The great majority (N = 68) were parents of young children with disabilities.

Chapter 5 has been divided into six sections. Each one summarizes and discusses the results and puts forward implications and recommendations for practice and research. The first section discusses Research Question # 1: What are the preliminary coefficients of reliability and validity of the Spanish Questionnaire on Resources and Stress QRS – short version? The second section discusses Research Question # 2: What relationships exist among stress, cultural variables, and demographic variables in a sample of immigrant Latino and European American parents of young children with disabilities? The third section discusses the null hypothesis: There are no differences in the levels of stress of immigrant Latino and European American parents of children with disabilities and it also discusses the hierarchical multiple regression models utilized in the prediction of stress for each cultural group. The fourth section discusses the results from the analysis conducted with the qualitative data. The Ecological Model of Human Development (Bronfenbrenner, 1979), the Transactional Model of Stress and Coping (Lazarus & Folkman, 1984), and the Orthogonal Cultural Identification Theory (Oetting & Beauvais, 1990) provided a theoretical framework for the aforementioned analyses. The fifth and sixth sections present, respectively, the limitations of the study and conclusions.

Research Question # 1: What are the preliminary coefficients of reliability and validity of the Spanish Questionnaire on Resources and Stress – short version?

The significance of this research question is better comprehended in the context of providing culturally responsive family intervention, which can only take place when the needs of individuals are assessed in their native language (Padilla & Medina, as cited in Carrol, 2001). For early intervention/early childhood special education service providers in contact with culturally diverse families, this recommendation is of surmount relevance, particularly when it comes to the Latino population who holds the highest rate of non proficiency in English (U.S. Census Briefs and Special Reports, 2000). The first research question responded to the need for making available psychometric instruments in the native language of the respondent that could be utilized by practitioners in the identification of areas of parental strength and potential coping with the demands associated with raising a child with disabilities and to identify areas of high stress that could then be linked to intervention programs. Translating the Questionnaire on Resources and Stress – QRS (Holroyd, 1987) into Spanish responded to this general need and allowed data collection from monolingual Latinos with the purpose of exploring their experiences of parenting a child with disabilities and comparing them to those of European American parents.

Seventy six Latino immigrants were recruited for the purpose of translating and validating the QRS in Spanish. First, the recommended procedures given by Prieto (1992), of forward and back translations, were followed. These

translations were carried out by three native target language bilingual individuals. Second, the Spanish version was field tested for language and cultural bias with the participation of 15 Latino parents, most of whom were parents of children with a typical development; and whose role was that of cultural informants checking for clarity of content and linguistic appropriateness (Salas-Provence et al., 2002) and identifying inaccurate, unfamiliar or intricate words, phrases, or sentences. Third, preliminary statistical validation of the Spanish QRS was conducted with data collected from 58 Latino parents, 18 were parents of children with a typical development and 38 were parents of children with disabilities. The coefficient of reliability was established to be .75 and the coefficient of criterion validity .90. Additional calculations were performed in order to determine the coefficients of reliability and validity for each one of the QRS' 11 scales. As Holroyd (1987) had warned, some of these coefficients tended to be weaker due to the smaller number of items involved in the calculations (i.e., six per scale) and the level of response variability may have furthermore contributed to this outcome (Anastasi, 1968). This was particularly the case with measurements of reliability for scales I (Dependency and management), III (Limits on family opportunities), VI (Lack of personal reward), VII (Terminal illness stress), and X (Preference for institutionalization) in which none of these scales were found to be statistically significant (See Table 4.5). Calculations for the other scales produced moderate levels of reliability primarily at $p < .001$. Nonetheless, measures of criterion validity were statistically significant for all scales, for the most part the coefficients were significant at $p < .001$ (See Table 4.5).

The above procedures provided the needed preliminary validation of this Spanish version of the Questionnaire on Resources and Stress for the purpose of measuring stress among Spanish-speaking parents of children with disabilities as well as for making comparisons between the two culturally diverse populations that were targeted in this study (i.e., European Americans and Latinos).

Making available the Questionnaire on Resources and Stress in Spanish can constitute a valuable tool for practitioners. First, the stress profile that results from the QRS provides insight about the parents' level of functioning in their roles as caretakers of a child with disabilities, family members, and professionals; it also provides insight into the quality of family relationships and some of the expectations about the child's future. By collecting information from family members, practitioners can obtain an accurate and more comprehensive description of the psychological adjustment to the experience of rearing a child with disabilities at various levels of the family's microsystem, the context where the strongest predictors of child's developmental outcomes are found (Magill-Evans & Harrison, 2001; Brazelton, 1992). For example, besides the mental ability and structural integrity of the speech system, early language development is a function of child's exposure to written and spoken language provided by his primary caregiver, regularly one of the parents. Data collected with the QRS can provide an intimate look at the family's microsystem regarding its potential for supporting the child's development in this particular area. Second, the QRS in Spanish can be instrumental in expanding the family's mesosystem; that is, the liaisons between the family and service providers, by functioning as starting point

in the conversations geared toward identifying the family's priorities, strengths, and needs for intervention.

For researchers interested in utilizing the Spanish QRS, several methodological recommendations are given. First, regarding its validity, this instrument needs to be subjected to factor analysis in order to strengthen the psychometric equivalence. Factor analysis would determine whether item grouping in the culturally different sample are consistent with the intended scales, those that were established with the culture of origin (Stewart & Bond, 2002; Cancio, 2003). Second, regarding its content, the phrasing of a few of the QRS items (i.e., 5, 29, 30, 44, 50) are directed to respondents caring for an older child or an adult patient, which potentially creates a conflict in the scoring process when data are collected from individuals parenting young children with disabilities. The items in question ask specifically about skills that young children cannot perform and consequently respondents obtain a higher level of stress only because of the age of their children (e.g., item 5: ____ can get around in the neighborhood quite easily). Since these items cannot be modified without affecting the validity of the instrument, these 5 items could be left out for scoring purposes when comparisons between populations of parents of children with different ages take place. Third, regarding its format, in view of the fact that in many instances participants in this study reported having a difficult time deciding to whether respond "yes" or "no" to several of the QRS's items, a more suitable answering format could be either a Likert Scale or a Semantic Differential; again,

this would require to establish a balance act with the potential effects on the instrument's psychometric properties.

Research Question # 2: What relationships exist among stress, culture, disabilities, and demographic variables in a sample of immigrant Latino and European American parents of young children with disabilities?

This research question explored the relationships between the outcome variable stress and various predictor variables (See Tables 4.1, 4.2, and 4.3) highlighted by the literature on disabilities and stress, and it aimed at presenting a detailed picture of the experience of parenting a child with disabilities; while at the same time identifying areas of variability and universality between the experiences of Latinos and European Americans. In order to address this research question, descriptive statistics (i.e., mean, standard deviation, mode) and inferential statistics were utilized (i.e., Pearson product moment correlation, Spearman Rho correlation, t-Test, ANOVA, hierarchical multiple regression).

Data showed that across cultures more than 60% of participants were married and reported being satisfied with the current status of their lives.

Although this was a multiple diagnosis sample, participants had preponderantly a son diagnosed with either Down syndrome or autism. European American parents were slightly older ($M = 40.34$) than Latinos ($M = 35.63$); and across cultures men worked for longer hours than women on a salaried position ($r_s = .684, p = .001$), but this characteristic was particularly predominant among Latinos wherein 65% of women did not work compared to 41% of European American women. Education and combined annual income set these two

cultural groups apart. Latinos reported making a combined annual income of \$50,000 or less and high school was their modal level of education. The average combined annual income for European Americans was above \$50,000.00 and college was their modal level of education.

Regarding the effect of demographic predictor variables, data from this study substantiated the premise of the transactional model of stress and coping (Lazarus & Folkman, 1984) which emphasizes on the instrumental role played by the individual's process of cognitive appraisal in the stress experience. This study found that across cultures the most powerful of all demographic predictors of stress was appraisal of child's development ($r = -.609, p < .001$). Lower levels of stress were reported when parents judged that their child with disabilities was developing according to what was expected for the child's age. Data also showed that stress was lower when parents appraised their lives as satisfying ($r_s = -.413, p < .001$), which was another subjective appraisal. Life satisfaction has been described an adaptational outcome (Lazarus & Folkman, 1984), a buffer to stress, that refers to the level of matching between the goals an individual sets in life and the degree of their achievement (Browne & Bramston, 1989). This study found that life satisfaction was higher when Latinos had a son with disabilities ($r_s = .496, p < .01$) while European Americans reported a higher level of life satisfaction when they had a daughter ($r_s = -.422, p < .05$). This finding merits further research to explain why the child's gender had such different effect across cultures.

Regarding the effect of cultural predictor variables, Latino men and women equally manifested strong identification with their own culture (i.e., native macrosystem); which refers to the cultural practices, beliefs, norms, feelings of respect, competence, and membership to the Latino community ($M_m = 22.7$; $M_f = 21.5$). However, despite the fact of having lived in the US for about a decade ($M_m = 11.44$, $M_f = 7.97$), Latinos reported moderate levels of cultural identification with mainstream American culture ($M_m = 12.5$; $M_f = 12$) (i.e., host macrosystem). This combination of high and low cultural identification with these two cultures is an indication of strong identification and adjustment largely with only the Latino culture (Oetting & Beauvais, 1990).

Though acculturation has been described as a process that occurs any time immigrants come in contact with a host culture (Sandhu et al., 1996; Michelson, 2003) and that it may take up to three generations to occur (Sanders, 2002), data from this study showed no association between the number of years immigrants have spent in the US and the level of cultural identification with mainstream American culture; instead, the latter might be a function of the quality of exchanges with members of the host culture.

This might be primarily because cultural identification with a host culture is described as being strongly associated with the development of friendships with natives from the host culture (Oetting & Beauvais, 1990; Oetting, Donnermeyer, Trimble, & Beauvais, 1998) and with active participation in the host community (Oetting et al., 1998), in that way, there are several factors that can potentially interfere with its development. First, proficiency in the language spoken by the

host culture can facilitate the quantity and quality of the exchanges between immigrants and locals. Second, the host culture's attitude toward migration will moderate their exchanges with Latino immigrants. Third, the immigrant's socioeconomic status determines how socially close he will be to the white majority (Neckerman et al., 2000). Participants in this study were primarily undocumented immigrants (80%), not proficient in English (92%), with an income that put them below the middle-class socioeconomic status, and who had voiced having negative encounters with members from the host culture (discussion of qualitative data comes later in this chapter); all of which may certainly interfere with the cultural identification process as were described by Oetting and collaborators (1998).

It is of particular relevance to mention that the setting of this study, a Midwestern state, is described as being socio-politically conservative and the social exchanges experienced by Latino immigrants with locals may have been tainted by cultural conservatives fearing that "something essential about the American character is vanishing under the crosscurrents of multilingualism and demographic change and ethnic pluralism" (Cloud, Allen, Burger, Kettmann, & Padgett, 2005, p. 33). Although migration in this region is not a new social phenomenon, in recent years it has been more substantial as neighboring states (i.e., Texas) faced higher volumes of migration and, consequently, immigrants faced higher levels of job competition. The above scenario may be tangentially explaining why Latino parents in this study reported low levels of identification with the values, beliefs, and other life practices of the European American culture

(ciAng1, $r = .433$, $p < .05$). It is clear that the immigrant's mesosystem, particularly the social connections with members from the host culture, is crucial for the development of an orthogonal cultural identity.

Of interest was the finding that European American women reported higher levels of cultural identification with their own culture ($M = 20.7$) than did their male counterparts ($M = 16$). Although this study did not aim at delving deeply into the cultural identification issues of members of the host culture, it was an unexpected outcome and further research may shed some light onto this phenomenon.

The Questionnaire on Resources and Stress decomposes the global variable of stress into three categories of personal stress, family stress, and index case stress, the following segments provide a brief discussion about the findings regarding each one of them.

First, personal stress is described as resulting from the responsibilities the parent assumes in the care of the child with disabilities and the limitations these responsibilities impose on personal growth and development. Results showed that for Latinos there were four variables that functioned moderately as resources for coping with personal stress; these were, appraisal of the child's cognitive development ($r = -.459$, $p < .001$), appraisal of the child's communication development ($r = -.343$, $p < .01$), the parent's level of education ($p_r = .338$, $p < .05$), and the age of the child ($r = .314$, $p < .01$). Development of child's cognitive and communication skills may be translating into minor or less complex care giving demands and responsibilities for the parent; likewise, caring for a very

young child with disabilities may provide a major sense of control and hope for the parent who may consider that there are still multiple opportunities for intervention and rehabilitation in the years to come. These findings emphasize on the crucial role that early intervention plays on families' expectations for child's developmental success as well as families' well-being. The association between personal stress and the fourth variable in this group is in opposition to findings from other studies showing that higher levels of education are associated with lower levels of stress (e.g., Little, 2002). In this study, Latino women with higher levels of education reported higher levels of personal stress. The role that education may play among immigrants is very interesting; immigrants, particularly those who are undocumented and have attained higher levels of education prior to migration, may be more vulnerable to the impact of barriers such as language and the utter inability to transfer their academic credentials to be utilized in the host culture (Neckerman et al., 2000), and consequently, their possibilities for personal and professional development are dimmed. Without the means for transferring academic credentials into the host culture there is no possible continuation of a professional career and the consequent socioeconomic improvement associated to a profession must be also ruled out. Among European Americans the best predictor of low personal stress was a high level of life satisfaction ($r_s = -.514, p < .01$).

Second, family stress is a category that reflects the preoccupation about the quality of family relationships, the presence of conflicts among family members, and lack of opportunities for socialization with outside acquaintances

or extended family; it also reflects the financial status of the family and the available opportunities for growth as a group. Results demonstrated that Latinos' levels of family stress were associated with several predictor variables; out of which only the five strongest correlations are included in this section. These variables were, the number of years living in the United States ($r = -.509, p < .001$), the level of life satisfaction ($r_s = -.472, p < .01$), the Body Mass Index of the respondent ($r = .421, p < .05$), the parent's appraisal of child's adaptive development ($r = -.416, p < .05$), and the level of cultural identification with own culture – Level 3 ($r = -.379, p < .05$). On average, Latinos in this study had spent roughly a decade living in the United States; which seems to be enough time for parents to learn how to access resources from their own community as well as for learning to navigate the socioeconomic system of the host culture (Oetting & Beauvais, 1990). Time spent is a variable closely related to the level of cultural identification with the Latino culture – Level 3, which refers to the feelings of competence, belonging, respect, and overall success in their own community. The process of getting acquainted with the Latino community takes time, considering that this is not a community composed largely by co-nationals but by individuals as diverse as the number of countries in Latin America. Of course, there is the immediate bond of shared language; yet, an immigrant arriving to the United States requires time to become acquainted with individuals that may differ from him in an array of other aspects that go beyond the common ground of language. As it was discussed earlier, the Latino concept aims at unifying individuals who may culturally differ to a great extent. BMI played an

unanticipated role in this category of family stress; results have shown that BMI increases as parents work for fewer hours on a salaried position ($r_s = -.325$, $p = .001$), making it difficult to elucidate whether family stress among Latinos might be in reality due to job-related issues. The fact that the majority of Latino women do not work and that some of them have higher levels of education (35%), could all be making Latino women feel dejected in their role as homemakers and thus inflating the real role played by the respondent's BMI on family stress. Finally, the role of parent's appraisal of child's development could be better understood by bringing to the discussion results from this study showing that, in their role of care givers, women reported more personal burden than men. This burden is for the most part associated to the level of care giving responsibilities that are commonly assumed by mothers of children with disabilities, and adaptive development is particularly relevant because it refers to those skills necessary to independently perform activities of daily living (e.g., showering, toilet training, tooth brushing, undressing) which could become physically draining for the care giver when the child's development is highly compromised.

Interestingly, family stress for European Americans was only associated with appraisal of child's cognitive development ($r = -.356$, $p < .05$). This finding is further discussed in section 4 of this chapter.

Index case stress is the third, and last, category of stress and it reflects the preoccupation for the child's mental and physical condition and his capability for independent living. Among Latino parents, the only relevant predictor was appraisal of child's development ($r = -.749$, $p < .01$), particularly motor and

adaptive domains. Similarly, European Americans reported lower levels of index case stress in association with higher levels of appraisal of child's development ($r = -.534, p < .01$). In addition, two other variables were moderately relevant; one was the age of the child ($r = -.393, p < .05$) showing that the younger the child the lower the level of this category of stress and the other predictor was the level of life satisfaction ($r_s = -.390, p < .05$).

This section has provided a better understanding of the types of relationships that exist among disabilities, stress, and various demographic and cultural predictor variables. In particular, variables that were found to be highly relevant cross culturally were appraisal of child's development and life satisfaction, the latter being associated with gender of the child. Culture specific predictor variables were gender of the child and cultural identification with own culture. For Latinos, personal stress was associated with the child's cognitive and communication development, the parent's level of education and the age of the child; family stress was associated with the number of years living in the United States, the level of life satisfaction, the parent's BMI, the child's adaptive development, and the level of cultural identification with the Latino culture (Level 3); finally, index case stress was associated only with the child's development in general, particularly motor and adaptive developmental domains. For European Americans, personal stress was found to be associated solely with life satisfaction; family stress was associated only with child's cognitive development; and index case stress was found to be associated with appraisal of child's development, the child's age and the level of life satisfaction.

Considering that this study has shown that a critical predictor of parents' adjustment to the experience of raising a child with disabilities is the child's rate of development, practitioners need to take the time to explore some important issues cross culturally.

First, explore whether parents have received training about practical ways to stimulate their child's development that could be easily embedded in their daily activities and would not dramatically alter the natural flow of their established family routines.

Second, explore whether the child's quality and rate of development is being discussed periodically with parents and whether developmental outcomes are continuously evaluated and compared against the objectives of the child's educational program. In doing this exploration, practitioners should take a candid look at the means utilized for the delivery of this information. Meetings to review the Individual Family Service Plan or the Individualized Education Program are crucial for families because are major opportunities for getting updated reports regarding the child's current status of development, these meetings are also valuable occasions for parents to ask questions related to various developmental issues. Practitioners may place less emphasis on presenting reports with abundant statistical data that may not be easily translated into an accurate picture of the child's progress; parents may benefit from concrete examples of the child's current developmental status and how these compare to the program's developmental goals. It is always more effective to ask parents about

the type of information it would help them to better gain an understanding of the child's progress.

Third, explore whether the child's intervention program reflects parents' priorities. As it will be later discussed, this study has shown that parents from different cultures placed greater emphasis on different areas of their child's development. For instance, while European Americans seemed to emphasize on cognitive and communication development, Latino parents do so with motor and adaptive development. Nevertheless, this is not an indication that the other developmental domains lack relevance to families; it is an indication that these seem to be culture-specific child's developmental priorities for families and special attention should be placed on them.

Fourth, as a way of expanding the Latino family's mesosystem, garnering a larger social network through parent-coach or mentor programs, as well as parent support groups in where Latino families and native families from mainstream culture participate together. This expanded social network would exert a positive impact on parents' ability to cope with stress and it would also enhance their acculturation process.

Cross-cultural research with families of children with disabilities would benefit from research suggestions made by Lazarus and Folkman (1984) and measure separately, the parent's cognitive appraisal of child's development (i.e., subjective variable) and compare it with a formal type of assessment (i.e., objective variable), for instance The Peabody Picture Vocabulary Test. This is done with the purpose of exploring their level of concordance; measuring the

objective and subjective rate of development could explore the parent's level of accuracy in appraising their child's development and determining whether some individuals may be using overestimation of child's development as means for coping with the stress. If that were the case, research could further explore the mechanisms by which this behavior could affect the effectiveness of intervention programs in general; and the rate of accomplishment of child's developmental objectives in particular. Additionally, it is of interest to determine the culture-specific effect that various demographic variables have on stress, particularly the gender and age of the child and their impact on stress and parenting skills.

International studies are also in order as a way to better explore the phenomenon of being exposed to two parallel ecological environments, as it is the case of immigrant parents; in this case, researchers interested in the immigration experience and their impact on parenting should analyze the role played by the native macrosystem (i.e., country and culture of origin) and the host macrosystem (i.e., host country and culture). In attempts at delving deeper into the parenting experience of Latinos, comparisons between immigrant Latino parents in various countries and Latinos living in their countries of origin may present a more accurate picture of the role played by culture, cultural identification, and that of the immigration experience. Likewise, cross-cultural comparisons of groups of parents from different nations could shed light on the suggestion that parents from developing countries may report lower levels of stress than parents from developed nations (e.g., Padeliadu, 1998).

There are various potential theoretical and policy extensions from the present study. First, why cultural identification with the host culture could have correlated negatively with stress? The orthogonal cultural identification theory (Oetting & Buvais, 1980) argues that acculturation, the process by which an immigrant becomes culturally identified with the host culture, brings psychosocial wellbeing to the individual. Latinos in this study have clearly acculturated to mainstream America; specifically, Latinos in this study would be considered integrated to the host culture (Oetting, 1993; See Table 2.1), but this level of integration is, for some unknown mechanisms, negatively associated with stress.

Second, does the quality of interactions between immigrants and natives from the host culture have a direct effect on the level of immigrants' acculturation and stress? This exploration would confirm whether time spent in the host country is not really a crucial factor in the acculturation process and how these negative social exchanges could be limiting parents' successful cultural adaptation. Third, research exposing why and what types of social services should be made available to families of children with disabilities regardless of immigration status is needed. This study comes out at the dawn of critical decisions regarding immigration legislation in the United States (e.g., Sensenbrenner Bill – HR – 4437: Border Protection, Antiterrorism, and Illegal Immigration Control Act), highly critical for undocumented immigrant parents of children with disabilities and it gives a special context to explore the implications and repercussions that this legislations might have on children born in the United States of undocumented immigrant Latinos. Undocumented status of the parent

may potentially hold barriers to the development of U.S. citizen children with disabilities due to the potential self-marginalization and isolation of the parent who may decline accessing special education services.

Null Hypothesis: There are no statistically significant differences in the levels of stress between Latino and European American parents of children with disabilities.

The core of this exploratory study was to determine whether there was any difference in the level of stress reported by Latinos and by European American parents of children with disabilities. In order to assess this hypothesis a t-Test for independent samples was utilized. The outcome of this test supported the null hypothesis and it was confirmed that there was no statistically significant difference ($t = -.242, p > .81$) between the levels of stress reported by Latinos ($M = 23.97, SD = 7.30$) and by European Americans ($M = 24.38, SD = 6.44$). Not only there was no difference on the general level of stress, but there was no statistically significant difference on any of the other 14 outcome variables of stress (i.e., personal, family, index case stress, 11 scales on the QRS). In both groups, moderate levels of stress were obtained considering that the highest possible stress score is 66.

Bearing in mind that the great majority of Latino parents in this study had been exposed to several stressors that could have impacted on their mental and/or physical wellbeing in different ways (i.e., had a child with disabilities, had left their home country, were separated from their extended family without clear date for reunion, lived in a host society without legal documentation, experienced

constant fear of the *migra*—immigration police—and potential deportation, did not speak English), the logical question that follows from the above results is why did their levels of stress equal those of mainstream middle class European American parents? Four explanations for coping are proposed and both, person and situation-related resources, may have been acting in conjunction.

First, the potential stressors Latinos in this sample faced were numerous, but this study found that parents' stress was associated with few of them. The estimation of the impairing potential these events may have had on Latino parents can be found in the quality of these parents' cognitive appraisal process (Lazarus & Folkman, 1984). According to the transactional model of stress and coping, Latino parents may have given to the aforementioned situations primarily a *challenge* value (as opposed to a *threat* value); that is, they may have appraised themselves as possessing the required resources to face those challenges without endangering their well-being. Lazarus and Folkman (1984) have also described that, "under the taxing condition of two or more difficult events going on at the same time, the events might not have an additive effect and in fact might in some subtle ways combine to reduce distress" (p. 113). Another possible explanation is given by Bandura (1977) and its concept of self-efficacy, this describes the belief in one's personal mastery over difficult circumstances. In view of that the majority of Latino parents were undocumented immigrants, it could be suggested that resilience might be one defining characteristic of this population. Coming to the U.S. illegally is an experience plagued with perils that not everyone is willing to face.

Second, high cultural identification, which has been associated to positive personal adjustment and well-being (Oetting & Beauvais, 1990), could be playing a buffering function for Latinos. In this study, Latino men and women reported equally high levels of cultural identification with their own culture, which would secure them a close position to the Latino community and, consequently, to its fluent provision of instrumental and emotional resources (Hartshorne, 2002; Vedhara et al., 2000). Some of the instrumental and emotional resources identified throughout the study were, for instance, the provision of interpretation support, babysitting, transportation, money loans, guidance for the navigation of services for the child with disabilities, job find, friendship, among others. Additionally, although the immigration experience shatters the physical presence of home country and family members, their psychological presence seems to remain unaltered and capable of playing a supportive role (Boss & Mulligan, 2003), which is another strong link to one's culture.

Third, income has been described as one powerful risk factor of stress (Lazarus & Folkman, 1984; Baldwin et al., 1995), and based solely on this characteristic and taking into consideration that the income difference between both groups was remarkable, Latinos in this study could have been expected to report higher levels of stress than European Americans. However, although in the U.S. Latinos are three times more likely to live in poverty when compared to non-Hispanic whites (Alvarez McHatton, 2004), few important issues ought to be kept in mind when conducting an analysis in where income seems to be explaining any variance. Firstly, participants in this study were voluntary

minorities (Ogbu, 1991 as cited in Cho et al., 2000), that is, they came to reside in this country in a voluntary manner, leaving their countries of origin deliberately. Secondly, immigrant parents in this study came from a region wherein level of poverty is usually translated into an income of about US\$2.00 per day (De Ferranti, Ferreira, Perry, & Walton, 2004) and as such, there ought to be dramatic quantitative as well as qualitative differences between the conceptualization and the experience of poverty in a developed country in comparison to the experience in a developing one. For an immigrant coming from a really economically deprived region of the world, the experience of what is commonly known as economic deprivation in the U.S., may be instead one of economic improvement. Thirdly, Neckerman and collaborators (2000) described that, “immigrants compare themselves not to affluent white Americans but to the relatively deprived co-ethnics who remain in the home country” (p. 948); in this study, when parents compared the quality of life they had in their home countries, their lives in the US was generally regarded as gaining in terms of financial situation. In fact, about US\$38 billion *migradollars* (i.e., remittances) are sent from the US to Latin American countries every year (Orozco, 2004) and Mexico is one of the five countries in the world that receives annually the largest amount of remittances (Spatafora, 2005), the home country of the majority of Latino parents in this study. Fourthly, the economic contribution Latino immigrants give to their families send also a message of achieved competence in the host culture and must have a positive impact on their sense of economic accomplishment. Fifthly, throughout the conduction of personal interviews it was observed that in

general, while European American parents gave a clear indication of being living above their economic means, Latino immigrants showed that for the most part they lived within theirs and still managed to contribute economically to their families back home. This is an important factor to take into consideration when analyzing the impact of income of parents' stress. Though it is certain that European Americans on average generated an income much higher than Latino immigrants, which would be putting them in a relative better position when facing a stressor (Baldwin et al., 1995), it is also certain that living above their economic means may function as a stressor per se. All these five arguments may explain why having a low socioeconomic status was not associated with higher levels of stress among Latino immigrants.

Fourth, the immigration experience in itself may contribute to the development of a sense of generalized competence among Latinos and become instrumental for coping purposes. Bronfenbrenner (1979) highlighted the crucial role in life played by transcontextual dyads, that is, the development of links among individuals who think and behave differently, whose values and beliefs are different from each other. This exposure to an environment that is culturally different from that of the individual can have a coping effect; it may stimulate to think about stressful transactions with the environment from different perspectives.

These have been tentative explanations to the results in the present study indicating that levels of stress between immigrant Latinos and European

American parents of children with disabilities were not statistically different. Nevertheless, this outcome merits further research.

Other comparisons on levels of stress were also conducted. For example, results from this study did not support the amply documented findings that mothers of children with disabilities experience higher levels of stress than fathers (e.g., Olsson & Hwang, 2001; Little, 2002). Across cultures, mothers and fathers reported equal levels of stress; however, mothers in both groups reported statistically significant higher levels of personal burden ($t(36) = 2.12, p < .05$). European American and Latino immigrant mothers equally reported being the child's main care giver, and the one that invested most of her time in issues that pertained to their child's development (e.g., school activities, therapy appointments). Research studies have described this burden as due to the personal and professional sacrifices that mothers tend to assume in the care of their child with disabilities (Hirose & Ueda, 1990; Olsson & Hwang, 2001; Bhagwanji & Suarez-Sousa, 2002). Professional sacrifices were, as it will be reviewed in the following section of this chapter, predominantly cumbersome for European Americans. Participant women in this study hold primarily part time jobs which may have also put them up for additional stress due to the fact that women in two-parent families have been found to be treated as full time mothers and wives by their husbands and full time employees by their employers (Bronfenbrenner, 1979).

Results from this study did also corroborate the common finding about parents of children with a typical development reporting statistically significant

lower levels of stress than parents of children with disabilities (e.g., Atkin & Ahmad, 2000; Reichman et al., 2000; Bhagwanji & Suarez-Sousa, 2002; McGlone et al., 2002; Esdaile & Greenwood, 2003) and they also supported the notion that there is a relatively consistent cross-cultural stress profile among parents of children with disabilities (Koegel et al., 1992). The profile of stress that resulted from this study (See Figure 4.12) is basically the same than the one reported by Koegel and collaborators (1992). This study suggests looking at each one of the scales of the QRS as the respondent's commitments (Lazarus & Folkman, 1984), that is, higher levels of stress on certain scales would show what is really important for the parent and that, due to this attributed level of importance, will determine what is stake if it becomes placed at risk. Likewise, scales with low levels of stress ought to be looked at as resources that service providers should capitalize on when developing intervention programs.

Participants in this study showed that their main sources of strength in facing the challenge of parenting a child with disabilities were found within the family and from the joy of parenthood itself. Although the birth of a child with disabilities may constitute a harmful experience for some, a challenge, or a threat for others (Lazarus & Folkman, 1984); across genders and cultures it is undeniable that it does also bring contentment to the parent and that, according to this study, does not generate a high level of stress.

The only statistically significant difference between cultures was found between men. Latino men reported a three times higher preference for institutionalization ($t(68) = 3.54, p < .001$) (See Figure 4.18). This result may

reflect more than a personal preference, a cultural practice since in many Latin American countries institutionalization is still in force.

To practitioners, the most important implication from these results is the acknowledgement that parenting a child with disabilities does not necessarily result on a high, debilitating, level of stress. For decades the body of research has reported stress in a manner that has indicated a serious negative effect on family functioning. This study acknowledges that families face various types of demands when it comes to raising a child with disabilities, yet, families seem to cope with the stressor in relatively effective ways.

Having said that, in the present study there was a clear indication that, cross-culturally, certain areas posited a potential need for family intervention. These areas were a) the cognitive development of the child, b) the prospective long span of care for the child, and c) the parent's level of physical and emotional weariness. The first area can be directly addressed by practitioners providing intervention/educational services to the child. The last two areas would demand the participation of policymakers, primarily in facilitating the provision of respite care services, which have been voiced by parents across cultures as being in great need.

Given the characteristics accompanying the immigration experience, practitioners should not generalize that all Latino families are surrounded by an extended family network; and thus benefiting from a large source of social and emotional support. For immigrant Latino families, in most of the cases, extended

family members remain in their countries of origin and communications are limited for the most part to phone calls.

Future research should be oriented at exploring the mechanisms by which immigrant Latino families cope with various potential stressors at the same time. It would be of interest to take a closer look at the concept of income and expand it in such a way as to include the rate of expenses as well (i.e., expenses above and below the family means). In this way, the effect of what has been always understood as income and its beneficial effect on family adjustment to stress may include a new dimension that would provide a more accurate picture of its effect on families.

It would also be of interest to explore the ways by which families of children with disabilities are able capitalize on the experience of stress. Approaching stress from a positive perspective was frequently suggested by Selye (1954) and Lazarus and Folkman (1984), whose theories stated that stress was a fact of life and thus, it should have to be utilized to the person's benefit not his detriment. Research has already shown that certain levels of stress generate proactive behaviors such as inducing parents to look for community resources and professional help (Holroyd, 1987).

Hierarchical Multiple Regression Model of Stress

Based on all the data collected and the body of current literature on stress and disabilities, this study attempted at building a model that would best predict the occurrence of stress by examining the predictive power of some of the demographic and cultural variables examined in this study. It is important to

keep in mind that the three most prevalent disabilities in this sample were, 1) mental retardation: Latinos: 45% and European Americans: 36%, 2) Pervasive Developmental Disorders – PDD: Latinos: 8% and European Americans: 47%, and finally, 3) Orthopedic Impairments: Latinos: 34% and European Americans: 6%. As it was shown on Table 4.13, European Americans' level of stress was associated preponderantly with appraisal of child's cognitive development while Latinos' level of stress was associated preponderantly with appraisal of child's motor development.

The goal in producing these regression models was to support the work of practitioners in early intervention/early childhood special education to be watchful to the incidence of certain characteristics associated with the likelihood of higher levels of stress. While results from this study found no statistically significant difference between the levels of stress experienced by Latinos and European Americans, detailed examination demonstrated that levels of stress experienced by these two cultural groups seemed to be associated, for the most part, to different predictor variables.

The current body of the literature on stress and disabilities has identified several critical predictor variables among which the mostly highlighted ones have been the following: gender of the parent (Olsson & Hwang, 2001), child's behavioral problems (Hodapp et al., 2003), child's functioning level (Noh et al., 1989, Abelson, 1999), marital status (Schilling et al., 1986; Olsson & Hwang, 2001), parent's level of education (Little, 2002), and financial status (Baldwin et al., 1995). With the exception of child's behavioral problems, this study examined

all the aforementioned variables. Nonetheless, only child's functioning level (i.e., appraisal of child development) was found to have a powerful effect for predicting stress when examining its combined effect with other variables.

Among Latinos, 66% of the variance in stress was explained by knowing the respondent's appraisal of child's motor development, the level of cultural identification with host culture (only Level 1 – values, beliefs), and the level of cultural identification with own culture, in descending order. Clearly, this hierarchical multiple regression model predicts that Latino parents who appraise their child's motor development as closer to the expected for the child's age, who report low incorporation of European American values and beliefs, and have a higher level of cultural identification with their own culture will experience lower levels of stress when raising a child with disabilities. For Latino parents, cultural predictor variables were playing a crucial role in their ability to deal with the stress associated to parenting a child with disabilities. An explanation for this model follows.

The Latino culture described as collectivist; is a culture that views the group, particularly the family, as its most valued institution in which the well-being of everyone is more important than that of the individual. These cultural characteristics apply most of all to Latinos from rural areas, as those living in larger cities tend to incorporate more Western-oriented cultural practices; Latino participants in this study came largely from rural areas in their home countries. Nevertheless, in general, Latinos place great emphasis on member interdependence (Salas-Provence et al., 2002), and to the role each individual

plays in the group. Is in this context that it may be better understood why child's motor development took precedent over other developmental domains, considering that there was a large proportion of children with mental retardation (45%) and a smaller, yet important, proportion of children with orthopedic impairments (36%).

In a collectivist society, children not only learn about cooperation, obedience, and the importance of a group identity, but they at an early age also learn crucial survival skills and actively participate and contribute to adult work (Bharati, 2000). Although Latino parents after migrating to the US are no longer living in a collectivist society, yet the influence of their native macrosystem, where they spent their formative years, does not vanish. The Latino behavior, values, beliefs are preserved regardless of their moving into a host, industrial, culture; and so are their child rearing practices and the expectations about children's performances and contributions. Motor development, the child's ability to operate the muscles of his body, is the most visible of all developmental domains at early ages. From the moment a child is born, motor development is amply used by observant parents and family members as a reference to the child's potential for *doing* things. In this regard, motor development may have been used by Latinos to assess whether their children had the potential for actively participating and contributing to the family and the group in various family and community chores.

The heavy load cultural predictor variables have on this regression model could have been anticipated from the discussions in the preceding sections.

Latinos are restricted in their ability to perform ecological transitions (i.e., access to new settings in the host culture) due to their absent or limited command of the English language, a problem that intensifies when considering that “unlike in several European nations, which are tolerant of linguistic diversity, in the United States the acquisition of non-accented English and the dropping of foreign languages represents the litmus test of Americanization” (Portes & Rumbaut, as cited in Wolfe, 1990). Thus, their connections with the host culture are limited, their networks could be considerably smaller (i.e., mesosystem), and so their psychological growth and well being. Without language, only superficial connections with the host culture can be established and wrong interpretations of behaviors can take place, which can result in animosity between cultural groups. Immigrants may feel they are being disloyal to their own culture if incorporation of European American values or norms takes place (i.e., *ciAng1*), as it has been seen by the negative correlation this predictor variable had on the regression model.

On the other hand, identification with own culture and the interactions with the Latino community provide a sense of sameness, orientation, identity, and connectedness to the ecological environment, all of which ease the immigration journey (Yelen, 2000) and function as a source of support to the families. On average, Latinos had spent about a decade living in the U.S. which may be instrumental for adaptational purposes in various ways. On one hand, there are more chances for learning the language, learning about the host culture and how to navigate within it. On the other hand, they may have had more chances for

establishing connections with members from their own culture who can potentially show them the route to survival (e.g., how to get a job, how to change their immigration status, where to find services for their child with disabilities, where to apply for health services).

The regression model for European Americans is rather different. In this cultural group 67% of the variance in stress was explained by knowing the respondent's appraisal of child's cognitive development and the level of life satisfaction. In this group, the most prevalent disabilities were pervasive developmental disorders (47%) and mental retardation (36%). Clearly, this hierarchical multiple regression model indicates that those parents who appraise their child's cognitive development as closer to the expected for the child's age and who have a higher level of life satisfaction will experience lower levels of stress when raising a child with disabilities. Among European Americans, cultural identification did not play a role in their experience of stress. An explanation for this model comes next.

In industrialized societies a major part of childhood is spent preparing for work, and thus there is a much greater emphasis placed on prolonged formal schooling and on skill development in order to reach economic potential (Bharati, 2000). Particularly, the European American culture has been described as individualistic, one that places great emphasis on independence, initiative and development of individual identity (Bharati, 2000). The attainment of all of the previously mentioned characteristics relies heavily on cognitive capabilities.

The emphasis on intelligence is corroborated by a study conducted by Harkness and collaborators (2000). Results from this study showed that European American parents of young children, when compared to Dutch parents, placed great emphasis on the development of those skills that had to do with being independent, smart, self-sufficient, and curious. They also found that European Americans “often described their children in terms of their intelligence, which parents attributed to them at the earliest possible age. In talking about their children, these parents typically professed to be ‘amazed’ at their children’s abilities, which they found ‘remarkable’ by comparison with other children of the same age or in contrast to what they might have imagined a small child to be capable of” (p.25). On the contrary, Dutch parents were found to place the greatest emphasis on the child’s social qualities and the child’s ability to learn how to function successfully in the social world. Harkness and collaborators (2000) have argued that these differences are the qualitative manifestations of culture. This seems to be corroborated in the present study, in where European Americans placed greater relevance to child’s cognitive development.

Although life satisfaction has been described as an adaptational outcome (Lazarus & Folkman, 1984), it was a predictor variable included in this study without knowing much about it from previous research; that is, no study was found dealing with disabilities, stress, and including life satisfaction as a predictor. This study found that life satisfaction was negatively correlated with stress across cultures; but it was particularly relevant for European American parents, among whom it was found to be a potent predictor of stress. Further

research would provide a better understanding about how this variable is being defined by families.

In conclusion, these two regression models confirmed the relevance that culture has in understanding the experience of stress. Among Latinos the immigration experience, particularly acculturation, took precedent over the majority of demographic variables with the exception of appraisal of child's development. Predictors of stress among European American parents were exclusively demographic. Cross-culturally, cognitive appraisal was observed to have a crucial role in the experience of stress; for European American parents it functioned as predictor for the global level of stress, among Latinos it predicted personal stress.

For practitioners, these results have shown that when it comes to immigrant families, the acculturation process is a moderator variable affecting all life experiences and as such, it has the potential for affecting the effectiveness of intervention programs. Practitioners cannot work collaboratively and successfully with families without acknowledging the pervasive impact that the immigration experience has on their lives. Based on this, three recommendations for practice are formulated. First, developing cross-cultural competence is part of the cultural responsibility that practitioners assume when providing services to diverse families. Cross-cultural competence has been defined as the ability, "to conduct one's professional work in a way that is congruent with the behavior and expectations that members of a distinctive culture recognize as appropriate among themselves" (Green, 1982, p.52 as cited in Lynch & Hanson, 1998). In

this way, cross-cultural competence denotes respect toward individuals from other cultures and acknowledges the fact that there is not just one right way to view the world (i.e., cosmovision) and behave on it. For instance, when working with Latino families a big emphasis needs to be given to interpersonal relationships (e.g., talking about what is going on in their marriage, issues with extended family, about the immigration experience) instead of coming with a matter-of-fact attitude trying to keep the meeting focused only on the task at hand (e.g., review the child's education program) (Lynch & Hanson, 1998). Cross-cultural competence may help practitioners in realizing how much of a culture shock the immigrant family may have experienced when first arrived to the US; this information will help practitioners developing more empathy toward, and willingness to support, immigrant families. Nevertheless, there is no greater learning experience for the purpose of developing cross-cultural competence, than leaving their home country and immersing, at least for a short period of time, in a completely different culture.

Second, practitioners need to acknowledge that the needs of immigrant families will be better addressed through a wrap-around model of services (Yelen, 2002) that respond not only to their needs as parents of a child with disabilities (e.g., family therapy), but to their needs as immigrants as well (e.g., legal advice). These wrap-around services should be family-centered and empowerment-oriented, facilitating parent participation in all aspects of planning and delivery of intervention programs. For example, knowing that immigrant families in many cases are reluctant to seek out resources for their families out of

fear of deportation or barriers such as language, one important consideration when providing services to undocumented immigrants is to identify what resources can be used by this population without jeopardizing any potential legal immigration application that may be processed later on (Lynch & Hanson, 1998); additionally, referrals for social services to these families should proceed after confirmation that there is no mandate for disclosure of immigration status, that is, that city employees are not obligated to report undocumented immigrants to law enforcement authorities.

Third, practitioners must remember that they support immigrant Latino families when explaining the beliefs, values, and norms of the host culture and discuss with them those of the Latino culture. In this way, a collaborative learning process takes place and the idiosyncrasies of the cultures are addressed in an informal, yet familiar and safe environment. For most immigrant families, service providers become the only members of the host culture with whom they establish social connections. Service providers are critical in showing acceptance, respect, and curiosity about culturally diverse families and become their hosts in an unfamiliar macrosystem.

Due to its value in predicting stress, research in the area of disabilities, culture, and stress should continue the exploration of the role played by life satisfaction and the ways in which it is conceptualized by the family, particularly European American families for whom its impact was stronger. Likewise, the definition given to disabilities across cultures needs to be further explored. This study did not address the definition of disabilities directly, but instead asked

parents about the impact of disabilities and those results are discussed in the next section of this chapter.

Research on cultural identification and stress should explore the limitations of the orthogonal cultural identification theory in explaining why identification with the Anglo culture may have produced a negative correlation with stress among immigrant Latinos. Additionally, research on the impact that the immigration experience may have on achievement would explore the moderating role played by immigration status on child's developmental outcomes, which would be critical information for practitioners. Finally, future research could approach culture in a more systematic way by utilizing Ogbu's (1995) components of culture: a) customary ways of behaving, b) assumptions, expectations and emotions underlying those customary behaviors, c) artifacts, d) institutions, and e) patterns of social relations. These components may provide a clearer and richer picture of the role played by culture on the experience of parenting a child with disabilities.

Qualitative Data Analysis: Basic Content Analysis

Qualitative data was collected during personal interviews and a basic content analysis was utilized with the purpose of retrieving themes that were common across cultures (i.e., global themes) and those that were particular to each one (i.e., culturalized themes). One global (i.e., Child as a positive impact on personal life) and five culturalized themes were identified; three from the Latino group and two from the European American group. In all cases,

culturalized themes were deficit oriented in nature, that is, voiced what parents thought they were missing. These are discussed next.

The global theme, *child as a positive impact on personal life*, presents a big commonality between cultural groups; all parents showed an inclination for voluntarily reporting the positive side of the experience of parenting a child with disabilities, corroborating findings from few studies (e.g., Stainton & Besser, 1998; Mullins as cited in Hastings & Taunt, 2002). In the present study, regardless of the level of stress, the child's level of development, or culture, participants suggested that parenting a child with disabilities resulted on personal growth, spiritual enrichment, and tolerance to people different from themselves, among other positive effects.

The first Latino theme was *negative experiences with health professionals in the US* and this finding seemed to support the argument that immigrants constitute a vulnerable group (Carr, 1994), one that can be subjected to inappropriate rendering of health services or that can become the target of culturally insensitive jokes. Professionals getting in contact with families of children with disabilities have been described as lacking information about disabilities, being unsympathetic, simply incompetent (Atkin & Ahmad, 2000), and highly insensitive when disclosing the diagnosis of disability to parents (Strauss, Sharp, & Lorch, 1995). This problem seems to become exacerbated when professionals provide services to immigrants, who do not speak English and have to rely on the presence of an interpreter. In this study, the few monolingual Latinos with a good understanding of English made negative

comments about interpretation services because they were able to assess the quality of the interpretation, yet they felt it was not appropriate to complain about its accuracy or to demand a change of service provider. Latinos in this study, for the most part, were afraid when it came to practice self advocacy for health and educational services, a cultural or situational trait that adds elements to their social vulnerability.

The second Latino theme was *reasons for immigration* and this also supported previously mentioned reports issued by world organizations such as the World Bank in where economic development has been proposed as the main motivator for leaving the home country (De Ferranti et al., 2004). Data from this study supported this claim and added an element which was identified by participants as being the huge catalyst in their decisions for moving to the US: getting better educational and health programs for their children with disabilities. However, the first theme has resonance within the context of this one for the reason that the idealized notions of easily accessible and state of the art services, that compelled families to migrate to the U.S.. may be far from reality. Immigrants must navigate health and educational systems that are extremely unfamiliar and complex, and the hurdles of language make matters worse. Finally, *missing home country* also supported previous claims about the immigration experience (e.g., Hovey, 2000). While the European American culture places great emphasis on the nuclear family, the Latino culture, with its collective nature, places a great deal of importance to the extended family, most of whom are left behind when departing from home country. These family

members stop playing the crucial role of providing stability and emotional support as they use to prior to migration. Interviewed parents reported missing three crucial issues from home country: first, the physical presence of family members; second, the freedom that comes with being a rightful citizen; and third, the sense of belonging and ownership to the land. Clearly, Latino parents in this study felt challenged by issues related to the immigration experience. An immigrant's journey is loaded with challenges of various kinds that become intensified with the presence of compounding variables such as racism and classism (Shorris, 1992 as cited in Yelen, 2002), both which may be found most commonly in culturally conservative areas in the country.

Although the Latino culturalized themes gave an indication of negative experiences with natives from the host country, the personal interviews revealed that Latino immigrant families were content, satisfied, and not obviously affected in their self-esteem by these negative experiences. This finding may give an indication that, since immigrants are self-selected, they may possess better coping resources to deal with adverse situations. Some immigrants described calmly the difficult experiences they had to endure in order to get into the U.S. and stay, and describe with great pride and satisfaction their accomplishments and plans for the future.

On the other hand, European American themes reflected exclusively the parents' experience as individuals and the restrictions faced in their current lives in direct association to parenting a child with disabilities. The first theme was *restrictions in work/professional life* and the second was *restrictions in social life*,

both supported previous research findings (Hirose & Ueda, 1990; Carr, 1994; Olsson & Hwang, 2001; Bhagwanji & Suarez-Sousa, 2002). In this cultural group, a distinction based on gender needs to be made. The restrictions in professional life were voiced almost exclusively by women. It was particularly interesting to notice an indication of higher vulnerability among younger mothers who were starting college or half way into their programs when they gave birth to their child with disabilities. When faced with the demands of parenthood and disabilities, these young mothers had to either change career paths and settle for less demanding, and potentially less rewarding career options, or drop college altogether. Older women had mostly to settle for a lower number of working hours but within their fields of expertise since, because of their age, they had had more chances for completing up to graduate school prior to giving birth to their child with disabilities.

European American men and women amply discussed about what they considered to be dramatic limitations in their social lives. Many reasons were proposed: child's sensorial problems (e.g., easily overwhelmed by noise), child's unpredictable behavior, lack of extended family support, no trusted person available to care for the child for few hours, among others. The restrictions in social life equally referred to activities in where children were welcomed (e.g., going to a restaurant) and activities to which parents did want to participate alone (e.g., late outing to the movies).

These qualitative data have added to the understanding of the cross-cultural experience of parenting a child with disabilities and have particularly

shed more light into the experience of immigrant Latino parents. Copious narratives such as these could be garnered by practitioners as part of getting to know the individual experience of family members and provide individualized services. Practitioners need to explore the family's personal history; it does not suffice to learn about the parents' level of education, their marital status, their income, or any of the other commonly mentioned risk factors impacting intervention services. These family narratives would reveal the nuances and subtleties of culture as they happen on a daily basis in natural contexts and would show a better picture of how the world is seen through the parent's eyes.

The field of early intervention/early childhood special education could benefit from qualitative research, particularly from case studies and ethnographies. However, one big limitation that researchers would face relates to gaining access to the population of immigrant families. Future research should explore best practices in the disclosure of disabilities to culturally diverse families.

Limitations of the Study

This study faced a number of threats to its internal and external validity.

Sampling Limitations

Data were collected from a relatively small purposive sample (N=103) which may jeopardize the power of the study in a number of ways.

Subject Characteristics

First, each participant self-selected him/herself based on criteria unknown to the researcher. Whatever the reasons for volunteering to participate in this

study, these have the potential for creating a gap with those parents who knew about it and yet decided not to participate. Second, the great majority of participants in the Latino sample were of Mexican origin whose cultural content may vary from individuals from other Latin American nations; thus limiting the generalization of results primarily to individuals from this nation. Third, although this study has added to the understanding of the experience of parenting a child with disabilities and the role played by culture, the selection of Latino participants may have created a group that is mostly representative of the immigrant population, which was primarily undocumented, rather than the Latino population in general.

Location Threat

This study took place in a Midwest state that had recently become an emerging Hispanic state and consequently the experiences of Latino immigrants in this study may vary greatly from those of Latinos living in either established Hispanic states or states with a low rate of migration.

Testing Limitations

When it comes to data collection among the Latino sub sample, this study did attempt to perform preliminary validation of the short Spanish QRS. Although all procedures considered best practices in the translation and validation of psychometric instruments were performed, the available sample utilized for this purpose was relatively small. Also, errors in interpretation may have damaged the ecological validity of the qualitative data collected in this study.

All these limitations however could be balanced against the paucity of data in this area.

Conclusions

This study aimed at exploring the relationships among disabilities, culture and stress. For this purpose the short version of the Questionnaire on Resources and Stress (Holroyd, 1987) was translated into Spanish, preliminary validation was conducted with the purpose of facilitating comparisons between European American and monolingual Latino parents of young children with disabilities. Results showed that the Spanish version of the QRS was valid (.90) and reliable (.75). Levels of validity for each one of the eleven scales were high. Levels of reliability for each one of the eleven scales were moderate and reflected in most cases those of the original QRS in English.

Results have shown that the stress experienced by parents was associated to the complex interplay of environmental characteristics, cognitive appraisals, and culture. Three universalities in the experience of parenting a child with disabilities were found. The first one indicates that the parent's cognitive appraisal of child's development is the most powerful predictor of stress; regardless of culture, gender, or age of either parent or child. The second one indicates that in measuring stress with the Questionnaire on Resources and Stress, the levels of stress are similar across genders and cultures. The third one indicates that parents of children with disabilities show a similar profile of stress characterized by higher stress in the areas of cognitive impairment, life span care, and personal burden.

Although the levels of stress are similar across cultures, the predictors of stress are primarily culture-specific: the variables that contributed to coping with stress among Latinos (i.e., appraisal of child's motor development, cultural identification) are different from the ones that support coping responses among European Americans (i.e., appraisal of child's cognitive development, life satisfaction).

In view of the fact that there is a dearth of cross-cultural research in the area of disabilities, stress, and culture, this study has contributed to the early intervention/early childhood special education service providers and researchers by supplying information about the experience of raising a child with disabilities that pertains to families from mainstream America as well as immigrant Latinos. It is expected that this knowledge will support service providers in implementing culturally responsive intervention programs and researchers in stimulating replications and new studies that will further new knowledge in this area, particularly concerning the association between the subjective appraisal of child's development and parental stress.

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APPENDICES

APPENDIX A
LETTER OF CONSENT TO UTILIZE THE QRS

From: Jean Holroyd <holroyd@ucla.edu>
To: Ximena P Suarez
CC: tsimmons@louisville.edu
Date: Thursday - September 25, 2003 11:37 PM
Subject: Re: Request for authorization to use and translate the
Questionnaire on Resources and Stress

Dear Ximena Suarez-Sousa,

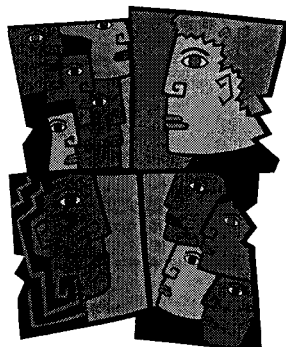
The QRS was translated into Spanish, with the assistance of Argentinian and Mexican translators. It was also "back translated" from the Spanish to English, to make sure that proper meaning wasn't lost. However, it has never (to my knowledge) been standardized on a Spanish speaking population, so the norms are all on English speaking people.

I am going to forward you, by attachment, the translated QRS in two different file formats (Word Perfect and Text). Let me know if you have any problems opening at least one of the files. Additionally, in a follow up mail I will forward a copy of the QRS manual by attachment. That should be all that you would need to do the research.

Sincerely,

Jean Holroyd, Ph.D.

APPENDIX B

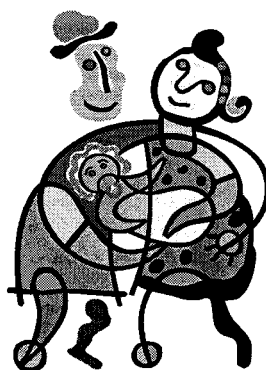


A RESEARCH ON PARENT, CULTURE AND STRESS

2005

PARENT SURVEY

Conducted by:
Ximena P. Suarez-Sousa, M.Ed.
University of Louisville, Kentucky



Your answers are completely confidential



WHAT IS THIS STUDY ABOUT?

In this study we want to explore what are parents' feelings about caring for a child with disabilities and how the parent's culture may influence this experience.



DIRECTIONS:

Your participation in this study is voluntary. We encourage you to answer all the questions. **Please, make sure not to write your name anywhere on the survey.**

This survey has two parts:

Part 1: Questionnaire: The questionnaire deals with your feelings about your child with disabilities (if you have more than one child with disabilities you need to select one of them for the purpose of providing your answers). There are many blanks on the questionnaire. Imagine your child's name filled in on each blank. Give your honest feelings and opinions. Please answer (mark) all of the questions even if they do not seem to apply. If it is difficult to decide if an item on the questionnaire is True or False, answer in terms of what you or your family feel or do most of the time.

The questions sometimes refer to someone who is older or younger or who has problems that your family member does not have. Nevertheless, these questions still can be answered True or False.

Example: "We get special funds because of _____'s problem." If you are responding about a family member who does not have any problem, the answer would be False because there is no problem for which you would get special funds.

Part 2: Background information: Information about you and your child.

When you have completed the survey, please return it to Ximena P. Suarez-Sousa in the envelope provided.

PART 1: Questionnaire
(Questionnaire on Resources and Stress by Holroyd, 1987)

**SIMPLY IMAGINE YOUR CHILD'S NAME IS WRITTEN
IN THE BLANKS PROVIDED.**

1. ____ demands that others do things for him/her more than is necessary ☐ T ☐ F
2. ____ is cared for equally by all members of our family. ☐ T ☐ F
3. Members of our family praise each other's accomplishments. ☐ T ☐ F
4. The doctor sees ____ at least once a month. ☐ T ☐ F
5. ____ would be in danger if he/she could get out of the house or yard. ☐ T ☐ F
6. People who don't have the problems we have don't have the rewards we have either.
☐ T ☐ F
7. Other members of the family have to do without things because of _____. ☐ T ☐ F
8. If ____ were more pleasant to be with, it would be easier to care for him/her. ☐ T ☐ F
9. I don't worry too much about ____'s health. ☐ T ☐ F
10. Our family agrees on important matters. ☐ T ☐ F
11. The constant demands for care for _____ limit growth and development of someone else in our family. ☐ T ☐ F
12. I worry about what will happen to ____ when I can no longer take care of him/her.
☐ T ☐ F
13. I am able to leave ____ alone in the house for an hour or more. ☐ T ☐ F
14. ____ is limited in the kind of work he/she could do to make a living. ☐ T ☐ F
15. I have given up things I have really wanted to do in order to care for _____. ☐ T ☐ F
16. I would not want the family to go on vacation and leave ____ at home. ☐ T ☐ F
17. There is no way we can possibly keep ____ in our house. ☐ T ☐ F
18. ____ can feed himself/herself. ☐ T ☐ F
19. As the time passes I think it will take more and more to care for _____. ☐ T ☐ F
20. We can afford to pay for the care ____ needs. ☐ T ☐ F
21. It bothers me that ____ will always be this way. ☐ T ☐ F
22. ____ uses special equipment because of his/her disability. ☐ T ☐ F
23. ____ is easy to live with. ☐ T ☐ F
24. The doctor sees ____ at least once a year. ☐ T ☐ F
25. Wheelchairs or walkers have been used in our house. ☐ T ☐ F

26. Caring for _____ has been a financial burden for our family. ☐ T ☐ F
27. I worry that _____ may sense that he/she does not have long to live. ☐ T ☐ F
28. We enjoy _____ more and more as a person. ☐ T ☐ F
29. _____ knows his/her own address. ☐ T ☐ F
30. _____ is aware of who he/she is (for example, a boy). ☐ T ☐ F
31. Sometimes I need to get away from the house. ☐ T ☐ F
32. Having to care for _____ has enriched our family life. ☐ T ☐ F
33. _____ doesn't do as much as he/she should be able to do. ☐ T ☐ F
34. Our family has been on welfare. ☐ T ☐ F
35. We take _____ along when we go out. ☐ T ☐ F
36. _____ is accepted by other members of the family. ☐ T ☐ F
37. _____ spends time at a special day center or in special classes at school. ☐ T ☐ F
38. Our family income is more than average. ☐ T ☐ F
39. Caring for _____ gives one a feeling of worth. ☐ T ☐ F
40. One of us has had to pass up a chance for a job because _____ could not be left without someone to watch him/her. ☐ T ☐ F
41. I worry about how our family will adjust after _____ is no longer with us. ☐ T ☐ F
42. The part that worries me most about _____ going on his/her own is his/her ability to make a living. ☐ T ☐ F
43. I worry about what will be done with _____ when he/she gets older. ☐ T ☐ F
44. _____ can get around the neighborhood quite easily. ☐ T ☐ F
45. There is a lot of anger and resentment in our family. ☐ T ☐ F
46. Our family has managed to save money or make investments. ☐ T ☐ F
47. We own or are buying our own home. ☐ T ☐ F
48. I am afraid _____ will not get the individual attention, affection, and care that he/she is used to if he/she goes somewhere else to live. ☐ T ☐ F
49. _____ is better off in our home than somewhere else. ☐ T ☐ F
50. _____ can describe himself/herself as a person. ☐ T ☐ F
51. It is easy to keep _____ entertained. ☐ T ☐ F
52. In the future, _____ will be more able to help himself/herself. ☐ T ☐ F
53. _____ needs a walker or a wheelchair. ☐ T ☐ F

- 66.a Please share with us in what ways (if any) your life changed since your son/daughter with disabilities was born. If you need more space to write, please use the blank spaces on the back of the Parent Survey.

This image shows a single sheet of white paper with horizontal ruling lines. The lines are evenly spaced and run across the width of the page. There are no margins, text, or other markings on the paper.

PART 2: Background Information

I. About yourself

67. Date of Birth _____

68. Gender: Female ☐ ¹ Male ☐ ²

69. Marital Status: Married ☐ ¹
Divorced ☐ ²
Separated ☐ ³
Single ☐ ⁴
Widow ☐ ⁵

70.
Indicate
your
height:

71.
Indicate
your
weight:

72. Number of Children (Please, specify how many of them have disabilities).

73. Ethnicity: African American ☐ ¹ Asian ☐ ² Hispanic ☐ ³ White Non-Hispanic
Other: _____ ☐ ⁵

74. Family Income per Year: \$15,000 or less ☐ ¹
15,001 - 25,000 ☐ ² 25,001 - 50,000 ☐ ³
50,000 - 75,000 ☐ ⁴ More than \$75,000 ☐ ⁵

75. Educational Level completed:

Elementary ☐ ¹ Number of years completed _____
Secondary ☐ ² Number of years completed _____
College ☐ ³ Number of years completed _____
Graduate ☐ ⁴ Number of years completed _____

76. Occupation _____

77. Working Hours per Week _____

78. How satisfied are you with your life at the present time?

Very Satisfied ☐ ⁴ Satisfied ☐ ³
Dissatisfied ☐ ² Very Dissatisfied ☐ ¹

79. Do you usually get sick? No ☐ ¹ Yes ☐ ² If **yes**, what type of health problems do you have? _____

II. About your son/daughter

80. Date of Birth _____ 81. Gender: Female ☐ ¹ Male ☐ ²

82. Disability _____ 82a. When was your child diagnosed? _____

82b. Is your child currently receiving special education services? Yes ___ No ___

If **yes**, please specify what services are these _____

Tell us about your son/daughter's development for each one of the following
(Please, use the Answer Options on this square)

83. Does your son/daughter pay attention,
learn, play and solve problems
as peers his/her age do? ☐

(Infant: reacts to sound,
5 year old: solves a puzzle
10 year old: solves a math problem)

84. Does your son/daughter initiate or respond to
interactions with adults or other peers and show
emotions that are common among children his/her age? ☐

(For example - Infant: waves bye-bye
5 year old: Shares toys with other children, 10 year old: Plays with
peers a table game)

85. Does your son/daughter have the ability to exchange information (verbal or
non-verbal) with adults or peers? ☐

(For example - Infant: Understands simple commands, 5 year old:
communicates mom what he needs, 10 year old: converses with dad about
school day)

86. Does your son/daughter have the ability to use his/her legs, arms, and
fingers for multiple purposes including mobility? ☐

(For example - Infant: Lifts head and chest off the ground
5 year old: runs after a ball, 10 year old: total command of own body)

87. Does your son/daughter have the ability to drink, eat, dress and perform
other activities that help him/her in taking care of himself/herself? ☐

(For example - Infant: reaches for the bottle, 5 year old: Puts on his
shoes, 10 year old: prepares his own breakfast)

Answer Options

On target for age	<input type="checkbox"/> 4
Fair	<input type="checkbox"/> 3
Delayed	<input type="checkbox"/> 2
Too Delayed	<input type="checkbox"/> 1

III. About your culture

(Orthogonal Cultural Identification Scale, Oetting & Beauvais, 1990; modified by Suarez-Sousa, 2004).

Please for each of the following 6 questions make sure to mark

ON EACH ONE OF THE A, B, C, D, AND E OPTIONS

88. Some families have special activities or traditions that take place every year at a particular time (such as holidays, parties, special meals, religious activities, trips, weddings or visits). When you were growing up, how many of these special activities did you family have that were based on...

A. Anglo culture: Not at all ☐ ¹ A little ☐ ² Some ☐ ³ A lot ☐ ⁴

B. Latino culture: Not at all ☐ ¹ A little ☐ ² Some ☐ ³ A lot ☐ ⁴

89. With your own family do you do special things together or have special traditions that are based on...

A. Anglo culture: Not at all ☐ ¹ A little ☐ ² Some ☐ ³ A lot ☐ ⁴

B. Latino culture: Not at all ☐ ¹ A little ☐ ² Some ☐ ³ A lot ☐ ⁴

90. Does your family live by or follow...

A. Anglo culture: Not at all ☐ ¹ A little ☐ ² Some ☐ ³ A lot ☐ ⁴

B. Latino culture: Not at all ☐ ¹ A little ☐ ² Some ☐ ³ A lot ☐ ⁴

91. Do you live by or follow...

A. Anglo culture: Not at all ☐ ¹ A little ☐ ² Some ☐ ³ A lot ☐ ⁴

B. Latino culture: Not at all ☐ ¹ A little ☐ ² Some ☐ ³ A lot ☐ ⁴

92. Is your family a success in the...

A. Anglo culture: Not at all ☐ ¹ A little ☐ ² Some ☐ ³ A lot ☐ ⁴

B. Latino culture: Not at all ☐ ¹ A little ☐ ² Some ☐ ³ A lot ☐ ⁴

93. Are you a success in the...

A. Anglo culture: Not at all ☐ ¹ A little ☐ ² Some ☐ ³ A lot ☐ ⁴

B. Latino culture: Not at all ☐ ¹ A little ☐ ² Some ☐ ³ A lot ☐ ⁴

94. In what country were you born? _____

95. How many years have you been living in the United States of America? _____

97. At this point in your life, how much stress would you say that you experience as a result of your son/daughter with disabilities?

25% or less ¹

26-50% ²

51-75% ³

75% or more ⁴

98. At this point in your life, how much stress would you say that you experience as a result of other factors (please specify at least one factor):

Factor _____

25% or less ¹

26-50% ²

51-75% ³

75% or more ⁴

Factor _____

25% or less ¹

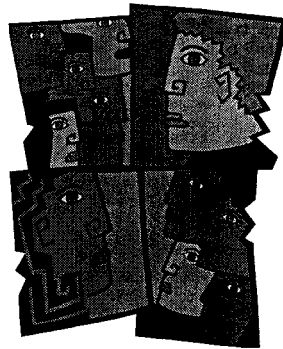
26-50% ²

51-75% ³

75% or more ⁴

*****THANK YOU VERY MUCH FOR YOUR PARTICIPATION!*****

APPENDIX C

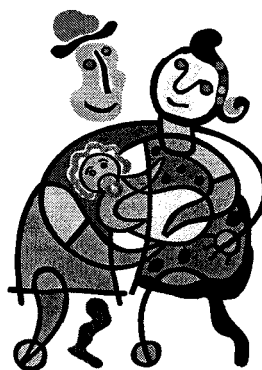


UN ESTUDIO SOBRE PATERNIDAD, CULTURA Y ESTRES

2005

ENCUESTA PARA PADRES

Estudio conducido por:
Ximena P. Suárez-Sousa, M.Ed.
Universidad de Louisville, Kentucky



Sus respuestas son totalmente confidenciales



¿SOBRE QUE ES ESTE ESTUDIO?

Con este estudio queremos explorar cuáles son los sentimientos de los padres y madres que tienen un niño o niña con necesidades especiales y cómo la cultura podría estar influenciando esta experiencia.



INDICACIONES:

Su participación en este estudio es voluntaria. Le animamos a que responda todas las preguntas. **Por favor, asegúrese de no escribir su nombre en este cuestionario, en ninguna parte.**

Esta encuesta tiene dos partes:

Parte 1: Cuestionario: El cuestionario explora los sentimientos que usted tiene hacia su hijo-hija con necesidades especiales (si usted tiene más de un hijo con necesidades especiales entonces tendrá que seleccionar uno para los fines de responder las preguntas de La Encuesta para Padres). Usted encontrará varios espacios en blanco en este Cuestionario. Imagine el nombre de su hijo-hija escrito en ellos. Proporcione sus más honestas opiniones y sentimientos. Por favor, responda (marque) todas las preguntas aún cuando éstas parezcan no aplicar a su caso en particular. Si le resulta difícil decidir si una pregunta en el Cuestionario es Verdadera o Falsa, responda en términos de lo que usted o su familia sienten o hacen en la mayoría de casos.

Algunas veces las preguntas se refieren a una persona mayor o menor o a alguien que tiene problemas distintos a los de su hijo-hija. Sin embargo, estas preguntas aún pueden ser respondidas Verdadero o Falso.

Por ejemplo: "Nosotros recibimos ayuda económica debido a las necesidades especiales de ____." Si su hijo o hija no tiene necesidades especiales por las cuales podrían recibir ayuda económica entonces la respuesta sería Falso.

Part 2: Información Personal: Información acerca de usted y su hijo o hija.

Cuando complete La Encuesta por favor envíesela a Ximena P. Suarez-Sousa en el sobre que le llegó adjunto.

PARTE 1: Cuestionario
(Cuestionario de Recursos y Estrés, por Holroyd, 1987)

**SIMPLEMENTE IMAGINE EL NOMBRE DE SU HIJO O HIJA ESCRITO EN
LOS ESPACIOS EN BLANCO**

1. ____ exige que otros hagan por él/ella más de lo que es necesario. ☐ V ☐ F
2. Todos los miembros de la familia cuidan a ____ en la misma medida. ☐ V ☐ F
3. Los miembros de nuestra familia se felicitan los unos a los otros por sus logros. ☐ V
☐ F
4. El doctor ve a ____ por lo menos una vez al mes. ☐ V ☐ F
5. ____ estaría en peligro si saliera de la casa o del patio. ☐ V ☐ F
6. Las personas que no tienen problemas como los nuestros, tampoco tienen las gratificaciones que nosotros tenemos. ☐ V ☐ F
7. Otros miembros de la familia carecen de cosas debido a _____. ☐ V ☐ F
8. Sería más fácil cuidar a ____ si fuese placentero estar con él/ella. ☐ V ☐ F
9. Yo no me preocupo mucho por la salud de _____. ☐ V ☐ F
10. Nuestra familia se pone de acuerdo en los asuntos importantes. ☐ V ☐ F
11. Las constantes demandas para cuidar a ____ limitan el crecimiento y desarrollo de algún miembro de nuestra familia. ☐ V ☐ F
12. Me preocupa lo que sucederá con ____ cuando yo ya no pueda cuidarlo(la).
☐ V ☐ F
13. Yo puedo dejar a ____ solo en la casa por una hora o más. ☐ V ☐ F
14. ____ tiene limitado(a) el tipo de trabajo que pueda en el futuro realizar para mantenerse. ☐ V ☐ F
15. He abandonado cosas que realmente quería hacer por tener que cuidar a ____.
☐ V ☐ F
16. No quisiera que la familia salga de vacaciones y deje a ____ en casa. ☐ V ☐ F
17. No hay forma de que podamos mantener a ____ en nuestra casa. ☐ V ☐ F
18. ____ puede alimentarse por sí mismo(a). ☐ V ☐ F
19. A medida que el tiempo pasa, pienso que va a tomar más y más cuidar a ____.
☐ V ☐ F
20. Podemos pagar por el cuidado que ____ necesita. ☐ V ☐ F
21. Me molesta el hecho de que ____ vaya a estar siempre así. ☐ V ☐ F
22. ____ usa equipo especial debido a sus necesidades especiales. ☐ V ☐ F

23. Es fácil vivir con _____. ☐ V ☐ F
24. El doctor ve a _____ por lo menos una vez al año. ☐ V ☐ F
25. En nuestra casa se han utilizado sillas de ruedas o andadores. ☐ V ☐ F
26. Cuidar de _____ ha sido una carga financiera para nuestra familia. ☐ V ☐ F
27. Me preocupa que _____ pueda darse cuenta que a él/ella no le queda mucho tiempo de vida. ☐ V ☐ F
28. Nosotros disfrutamos de _____ cada vez más como persona. ☐ V ☐ F
29. _____ sabe cual es la dirección de su casa. ☐ V ☐ F
30. _____ está enterado(a) de quien es él/ella (p.e., varón de 14 años). ☐ V ☐ F
31. Algunas veces necesito alejarme de casa. ☐ V ☐ F
32. Tener que cuidar de _____ ha enriquecido nuestra vida familiar. ☐ V ☐ F
33. _____ no hace tanto como él/ella debería ser capaz de hacer. ☐ V ☐ F
34. Nuestra familia ha estado recibiendo asistencia social. ☐ V ☐ F
35. Cuando salimos a la calle llevamos a _____ con nosotros. ☐ V ☐ F
36. _____ es aceptado por otros miembros de la familia. ☐ V ☐ F
37. _____ pasa el tiempo en un centro de cuidado especial o en clases especiales en el colegio. ☐ V ☐ F
38. Nuestro ingreso familiar es mayor que el del promedio. ☐ V ☐ F
39. Cuidar a _____ le produce a uno(a) un sentimiento de mérito. ☐ V ☐ F
40. Uno de nosotros ha tenido que rechazar una oportunidad de trabajo porque _____ no tenía quien lo cuidara. ☐ V ☐ F
41. Me preocupa como nuestra familia se adaptará después de que _____ ya no esté con nosotros. ☐ V ☐ F
42. Lo que más me preocupa cuando _____ tenga que hacerse cargo de sí mismo(a), es su habilidad para ganarse la vida. ☐ V ☐ F
43. Me preocupa lo que pasará con _____ cuando él/ella tenga más edad. ☐ V ☐ F
44. _____ puede ir con mucha facilidad de un lado a otro en el vecindario. ☐ V ☐ F
45. Hay mucha cólera y resentimiento en nuestra familia. ☐ V ☐ F
46. Nuestra familia se las ha arreglado para ahorrar dinero o hacer inversiones. ☒ V ☐ F
47. Nosotros poseemos o estamos comprando nuestra propia casa. ☐ V ☐ F
48. Temo que _____ no reciba la atención individual, el afecto y el cuidado al que está acostumbrado(a) a recibir si se fuera a vivir a otra parte. ☐ V ☐ F
49. _____ está mejor en nuestra casa que en cualquier otra parte. ☐ V ☐ F

PARTE 2: Información Personal

I. Acerca de Usted

67. Fecha de Nacimiento _____

68. Género: Femenino ☐ ¹ Masculino ☐ ²

69. Estado Civil: Casado(a) ☐ ¹
Divorciado(a) ☐ ²
Separado(a) ☐ ³
Soltero(a) ☐ ⁴
Viudo(a) ☐ ⁵

70.
Indique
su
altura:

71.
Indique
su peso:

72. ¿Cuántos hijos(as) tiene? (Por favor especifique cuántos tienen necesidades especiales). _____

73. Etnia: Americano Africano ☐ ¹ Asiático ☐ ² Hispano/Latino ☐ ³ Blanco No Hispano ☐ ⁴ Otro: _____ ☐ ⁵

74. Ingreso Familiar al año: \$15,000 o menos ☐ ¹
15,001 - 25,000 ☐ ² 25,001 - 50,000 ☐ ³
50,000 - 75,000 ☐ ⁴ Más de \$75,000 ☐ ⁵

75. Nivel Educativo alcanzado:

Primario ☐ ¹ Número de años completados ____
Secundario ☐ ² Número de años completados ____
Universitario ☐ ³ Número de años completados ____
Post Grado ☐ ⁴ Número de años completados ____

76. Ocupación _____

77. Horas de trabajo a la semana _____

78. ¿Qué tan satisfecho(a) está usted con su vida en este momento?

Muy Satisfecho(a) ☐ ⁴ Satisfecho(a) ☐ ³
Insatisfecho(a) ☐ ² Muy Insatisfecho(a) ☐ ¹

79. ¿Se enferma con frecuencia? No ☐ ¹ Si ☐ ² Si su respuesta es **si**, qué tipo de problemas de salud tiene usted?

II. Acerca de su Hijo(a)

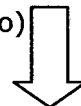
80. Fecha de Nacimiento _____ 81. Género: Femenino ☐ ¹ Masculino ☐ ²

82. Diagnóstico _____ 82a. ¿Cuándo diagnosticaron a su hijo(a)? _____

82b. ¿Está su hijo(a) recibiendo actualmente educación especial ? Si ____ No ____

Si respondió **si**, por favor especifique los servicios que está recibiendo

Cuéntenos un poquito acerca de cada una de las areas del desarrollo de su hijo o hija (Por favor, utilice las Opciones de Respuesta que figuran en este recuadro)



83. ¿Su hijo(a) presta atención, aprende, juega y

resuelve problemas como otros niños de su edad? ☐

(Por ejemplo - **Infante**: Reacciona a los sonidos,
niño de 5 años: Arma un rompecabezas sencillo,
niño de 10 años: Resuelve un problema de matemáticas)

84. ¿Su hijo(a) inicia o responde a las interacciones con adultos o niños de su edad y se emociona de la misma manera que los niños de su edad? ☐

(Por ejemplo - **Infante**: Hace "adios" con las manitos,
niño de 5 años: Comparte juguetes con otros niños, **niño de 10 años**: Con niños de su edad juega cooperativamente)

85. ¿Tiene su hijo(a) la habilidad de intercambiar información (verbal o no-verbal) con adultos or niños de su edad? ☐

(Por ejemplo - **Infante**: Entiente ordenes simples, **niño de 5 años**: Comunica a su mamá lo que necesita, **niño de 10 años**: Conversa con su papá sobre los acontecimientos en la escuela)

86. ¿Tiene su hijo(a) la habilidad para usar sus piernas, brazos, y dedos para multiples propósitos tales como mobilizarse de un lugar a otro? ☐

(Por ejemplo - **Infante**: Levanta la cabeza y pecho cuando se lo deja en el suelo, **niño de 5 años**: Corre detrás de la pelota, **niño de 10 años**: Tiene total control de su cuerpo)

87. ¿Tiene su hijo(a) la habilidad para beber, comer, vestirse y ejecutar otras actividades que le permiten cuidar de sí mismo(a)? ☐

(Por ejemplo - **Infante**: Sujeta el biberón, **niño de 5 años**: Se pone los zapatos, **10 year old**: Se prepara el desayuno)

III. Acerca de su Cultura

(Escala de Identificación Ortogonal de Cultura, por Oetting & Beauvais, 1990; modificado por Suárez-Sousa, 2004).

Por favor para cada una de las siguientes 6 preguntas

88. Algunas familias tienen actividades y celebran tradiciones que se llevan a cabo en cierto momento del año (como feriados, fiestas, comidas especiales, actividades religiosas, paseos, matrimonios o visitas). ¿Cuando usted estaba pequeño(a), cuántas de estas actividades las celebró su familia de acuerdo a la cultura ...

A. Anglosajona: Ninguna ☐ ¹ Muy Pocas ☐ ² Algunas ☐ ³ Muchas ☐ ⁴

B. Latina: Ninguna ☐ ¹ Muy Pocas ☐ ² Algunas ☐ ³ Muchas ☐ ⁴

89. Ahora, con su propia familia, ustedes celebran juntos tradiciones especiales que están basadas en la cultura ...

A. Anglosajona: Ninguna ☐ ¹ Muy Pocas ☐ ² Algunas ☐ ³ Muchas ☐ ⁴

B. Latina: Ninguna ☐ ¹ Muy Pocas ☐ ² Algunas ☐ ³ Muchas ☐ ⁴

90. Su familia vive de acuerdo a la cultura...

A. Anglosajona: No ☐ ¹ Muy Poco ☐ ² Algo ☐ ³ Mucho ☐ ⁴

B. Latina: No ☐ ¹ Muy Poco ☐ ² Algo ☐ ³ Mucho ☐ ⁴

91. Usted vive de acuerdo a la cultura...

A. Anglosajona: No ☐ ¹ Muy Poco ☐ ² Algo ☐ ³ Mucho ☐ ⁴

B. Latina: No ☐ ¹ Muy Poco ☐ ² Algo ☐ ³ Mucho ☐ ⁴

92. Su familia ha triunfado en la cultura...

A. Anglosajona: Nada ☐ ¹ Muy Poco ☐ ² Algo ☐ ³ Mucho ☐ ⁴

B. Latina: Nada ☐ ¹ Muy Poco ☐ ² Algo ☐ ³ Mucho ☐ ⁴

93. Usted ha triunfado en la cultura...

A. Anglosajona: Nada ☐ ¹ Muy Poco ☐ ² Algo ☐ ³ Mucho ☐ ⁴

B. Latina: Nada ☐ ¹ Muy Poco ☐ ² Algo ☐ ³ Mucho ☐ ⁴

94. ¿En qué país nació usted? _____

95. ¿Cuántos años lleva viviendo en los Estados Unidos de América? _____

97. En este momento de su vida, cuánto del estrés que siente lo atribuiría a su hijo(a) con necesidades especiales?

25% o menos ¹

26-50% ²

51-75% ³

75% o más ⁴

98. En este momento de su vida, cuánto del estrés que siente lo atribuiría a otros factores (por favor especifique por lo menos un factor):

Factor _____

25% o menos ¹

26-50% ²

51-75% ³

75% o más ⁴

Factor _____

25% o menos ¹

26-50% ²

51-75% ³

75% o más ⁴

*****!MUCHAS GRACIAS POR SU PARTICIPACION!*****

APPENDIX D
ADDITIONAL TABLES

Table 1

Mean, Standard Deviation, and Proportion Values for all Demographic Predictor Variables of Stress

Variable	Latino				European American			
	Male		Female		Male		Female	
	<i>M</i>	σ	<i>M</i>	σ	<i>M</i>	σ	<i>M</i>	σ
Age	38.83	3.76	34.29	7.09	41.00	7.43	40.00	5.56
BMI	25.40	6.77	28.57	4.37	26.56	5.07	26.95	6.02
Number of children	2.67	1.07	2.65	1.33	2.22	1.48	2.32	1.21
Age of child	5.67	4.66	5.89	4.80	7.34	4.32	7.67	4.20
Appraisal	15.40	4.93	14.18	4.48	15.78	2.82	13.04	4.19
Communication	3.00	1.25	2.68	1.13	3.00	0.87	2.13	1.06
Social	2.90	1.29	3.00	0.98	3.11	0.93	2.57	1.21
Cognitive	2.90	1.20	2.91	1.07	2.67	1.00	2.22	1.04
Motor	3.50	0.71	3.00	1.20	3.67	0.71	3.22	0.85
Adaptive	3.10	0.99	2.59	1.44	3.33	0.87	2.91	1.08
	%		%		%		%	
Marital status								
Married	100		84.6		100		95.7	
Divorced			3.8					
Separate			3.8					
Single			7.7					

Table 1 (Cont.)

	Latino		European American	
	Male	Female	Male	Female
	%	%	%	%
Education				
Primary	16.7	23.1		
Secondary	41.7	42.3	11.1	8.7
College	25	34.6	88.9	60.9
Graduate	16.7			26.1
Income				
\$15,000 or less	25	30.8		
\$15,000-25,000	33.3	38.5		
\$25,001-50,000	33.3	26.9	33.3	30.4
\$50,001-75,000	8.3		44.4	52.2
\$75,001 or more			22.2	13.0
Poverty line				
Below PL	41.7	50		4.3
Above PL	58.3	46	100	91.3
Working hours				
Above full time	--	--	33.3	8.7
Full time	91.7	3.8	55.6	21.7
Part time	8.3	15.4	--	21.7
Not Working	--	73.1	--	43.5
Life satisfaction				
Very satisfied	41.7	38.5	11.1	21.7
Satisfied	50	42.3	55.6	47.8
Dissatisfied	--	7.7	22.2	26.1
Very dissatisfied	--	--	11.1	--

Table 1 (Cont.)

	Latino		European American	
	Male	Female	Male	Female
	%	%	%	%
Frequent sickness				
Yes	16.7	7.7	11.1	34.8
No			88.9	60.9
Weight				
Underweight	--	--	11.1	4.8
Healthy weight	50	13	22.2	28.6
Overweight	40	52.2	33.3	33.3
Obese	--	30.4	33.3	28.6
Morbidly Obese	10	4.3	--	4.8
Gender of the child				
Male	66.7	61.5	55.6	52.2
Female	33.3	38.5	44.4	47.8
Disability of the child				
MR	41.7	46.2	33.3	39.1
OI	33.3	34.6	11.1	4.3
OHI	--	7.7	11.1	8.7
Au Spectrum	16.7	3.8	44.4	47.8
Unspecified	8.3	7.7		
Stress due to child				
25% or less	66.7	26.9	44.4	21.7
26-50%	8.3	23.1	33.3	30.4
51-75%	8.3	11.5	22.2	34.8
76% or more	--	26.9	--	13.0

Table 2

Mean, Standard Deviation, and Proportion values for all Cultural Predictor

Variables of Stress

Variable	Latino				European American			
	Male		Female		Male		Female	
	<i>M</i>	σ	<i>M</i>	σ	<i>M</i>	σ	<i>M</i>	σ
CI with own culture [†]	22.70	1.89	21.48	4.07	16.00	7.53	20.74	4.04
ci Level 1	7.70	0.68	7.59	0.80	5.11	2.42	7.13	1.46
ci Level 2	7.70	0.68	7.45	1.10	5.33	2.83	7.22	1.48
ci Level 3	7.30	0.95	7.05	1.96	5.56	2.46	6.35	1.80
CI with other culture ^{††}	12.48	4.45	12.04	4.25	6.11	2.67	7.43	3.88
ci Level 1	13.5	4.45	3.32	1.36	2.22	1.20	2.48	1.34
ci Level 2	4.20	1.99	2.86	1.28	2.11	1.05	2.43	1.34
ci Level 3	5.80	1.48	6.27	2.19	1.78	0.67	2.48	1.38

[†] L1 = Refers to the respondent's identification with traditions and other life practices of the mentioned culture, L2 = Refers to the respondent's level of active involvement in cultural activities and traditions with the mentioned culture, L3 = Refers to feelings of capability, respect, and competence in the mentioned culture. E.g., ciLat3 (cultural identification with Latino culture Level 3), ciAng1 (cultural identification with Anglo culture Level 1).

^{††} Either CIAng (Total Cultural Identification with Anglo culture) or CILat (Total Cultural Identification with Latino culture). Highest possible score: 24.

Table 2 (Cont.)

Variable	Latino		European American	
	Male	Female	Male	Female
	%	%	%	%
Years living in the US	11.44	8.03	7.97	6.63
Less than 10 years	58.3	65.4		
Ten years or more	41.7	34.6		
Country of origin				
Mexico	66.7	76.9		
Guatemala	16.7	11.5		
Venezuela	8.3			
Peru	8.3	11.5		

Table 3

Mean and Standard Deviation Values for Total Stress, Stress Categories, and QRS Scales

Variable	Latino				European American			
	<u>Male</u>		<u>Female</u>		<u>Male</u>		<u>Female</u>	
	<i>M</i>	σ	<i>M</i>	σ	<i>M</i>	σ	<i>M</i>	σ
Total Stress	21.58	7.96	25.08	6.85	21.78	5.61	25.39	6.56
Personal Stress	8.92	3.40	11.42	3.40	9.44	3.47	11.91	3.03
Scale IV	3.75	1.49	3.62	1.63	4.67	1.58	4.09	1.56
Scale VI	0.42	0.99	0.81	1.02	0.44	1.01	0.70	1.11
Scale VII	1.67	1.23	1.69	1.26	1.00	1.00	1.83	1.56
Scale X	1.08	0.52	1.50	1.18	0.33	0.50	0.70	0.82
Scale XI	2.00	0.85	3.81	1.58	3.00	1.00	4.61	1.12
Family Stress	4.42	1.93	5.96	2.72	4.67	2.24	6.22	2.63
Scale III	1.92	1.38	2.12	0.86	2.33	1.23	2.83	1.44
Scale V	0.33	0.49	1.08	1.44	0.56	0.88	1.26	0.70
Scale IX	2.17	1.12	2.77	1.55	1.78	1.20	2.13	1.25
Index Case Stress	8.25	3.98	7.73	3.35	7.67	1.94	7.26	3.37
Scale I	1.67	1.67	1.50	1.14	2.44	2.07	2.35	2.06
Scale II	4.67	1.56	4.23	1.80	4.22	2.05	3.74	1.98
Scale VIII	1.92	2.31	2.00	2.23	1.00	0.87	1.17	1.59

Table 4

Mean and Standard Deviation values of four selected Outcomes of Stress among Parents of Children with a Typical Development

Variable	Total Group ^a	
	<i>M</i>	<i>σ</i>
Total Stress	15.75	4.60
Personal Stress	7.95	2.40
Family Stress	3.80	2.19
Index Case Stress	4.00	2.29

^a N = 18

Table 5

Factors Contributing to the Level of Stress

Factor	Latino	European American
	%	%
Work	11.7	38.0
Finances	29.0	23.5
Marital	5.8	20.5
Family	17.6	5.8
Health	5.8	2.9
Racism	5.8	0
Aging	11.6	0
Migration	5.8	0

^a Frequency

CURRICULUM VITAE

Ximena P. Suárez-Sousa, M.Ed.
3184 NW Expressway
Oklahoma City, OK 73112

EDUCATION

- Doctor of Philosophy** **2006**
Curriculum and Instruction - Special Education
College of Education and Human Development - University of Louisville.
Dissertation Title: “Does Culture Matter? Exploring the Relationships among Parenting a Child with Disabilities, Cultural Identification and Stress in a group of European American and Immigrant Latino Families.”
- Master of Education** **2000**
Moderate/Severe Mental Retardation
College of Education and Human Development - University of Louisville.
- Bachelor of Science. Psychology** **1992**
Cayetano Heredia Peruvian University. Lima, Peru.

EMPLOYMENT

- Adjunct Faculty (Graduate)** **2004 – 2005**
College of Education – Department of Teaching and Learning
University of Louisville
- Graduate Assistant/Instructor** **2000 – 2004**
Department of Teaching and Learning - College of Education and Human Development.
University of Louisville.
- Undergraduate level courses
EDSP 180 Introduction to Special Education
EDSP 181 Field Experience in Special Education

Graduate level courses

EDSP 540 Introduction to Exceptional Children

EDSP 638 Educational Management of Children with Health, Physical and Multiple Disabilities

EDSP 639 Research Analysis in Special Education

EDSP 693 Consulting with Parents and Teachers of Exceptional Children

Graduate Research Assistant

1998 - 2000

Department of Teaching and Learning - College of Education and Human Development. University of Louisville. Louisville, KY. Assisted faculty members with research projects (Literature review, data collection, data entering, data analysis).

Bilingual Instructor

1998

Jefferson County Public Schools. Louisville, KY. Elementary school Spanish teacher.

Data Processor

1996

Informatics, Biostatistics, and Research Department. School of Medicine - Southern Illinois University. Springfield, IL. Processed research data.

Psychologist

1995-1996

Private Practice. Lima, Peru. Assessed cognitive development, adaptive behavior, social performance, and communication patterns of regular students, at-risk children and children with special needs. Conducted remedial therapy.

Trainer

1992-1995

Centro Ann Sullivan del Peru – CASP. Lima, Peru. Served as coach in the Center's vocational program for young individuals with autism. Developed individualized transition plans for supported employment in the community. Worked with children with disabilities developing independent living, community, and communication skills.

PUBLICATIONS

Bhagwanji, Y., & Suárez-Sousa, X. Using Holroyd's QRS to better understand parental stress. (2003). *EnVision: A Publication for Parents and Educators of Children with Impaired Vision*, 7, 2-4.

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Flores, J., Edge, D., Suárez-Sousa, X., & Hanse, B. (2000). Publication Survey Report. The 2000 United States Distance Learning Association (USDLA) Congress.

CONFERENCE PRESENTATIONS

Stress Profiles of Culturally Diverse Parents of Young Children with Disabilities. 04/2004
Council for Exceptional Children Annual Convention and Expo. New Orleans, LA

Applying Prospective Principles in Building Desired Futures 04/2004
Council for Exceptional Children Annual Convention and Expo. New Orleans, LA

Using Sociograms to Promote Classroom Inclusion 04/2003
Council for Exceptional Children Annual Convention and Expo. Seattle, WA

Stress Profile of Parents Caring for a Child with Disabilities: 04/2002
Exploring Peruvians' and Americans' Ideas about Parenting a Child with Disabilities
Spring Research Conference - University of Cincinnati. Cincinnati, OH

Stress Profile of Peruvian Parents Caring for Children with Autism 04/2002
Paper Talk I – Education Graduate Student Association University of Louisville.
Louisville, KY

Training Opportunities and Needs in Early Intervention/ 10/2001
Early Childhood Special Education: Implications for Kentucky
Kentucky Association for Early Childhood Education Fall Conference. With Bhagwanji, Y., and Vasquez-Colina, M. Lexington, KY

PROFESSIONAL DEVELOPMENT

Multicultural Early Childhood Team Training – MECTT 06/2001
George Mason University. Fairfax, WV. Participated as a State of Kentucky Representative. Received training on how to infuse multicultural elements in early childhood programs.

Future Professors Program	2000-2001
One-year program designed for doctoral students interested in higher education careers.	
University of Louisville	

UNIVERSITY SERVICE

Senator – Student Government Association	2002 - 2003
University of Louisville	

Senator at Large - Graduate Student Council	2002 - 2003
University of Louisville	

Student Representative - Faculty Senate Committee on Libraries	2002 – 2003
University of Louisville	

Member - Future Professors Program Advisory Committee	2002 - 2003
University of Louisville	

Student Representative - Research and Faculty Development Committee	2001
College of Education and Human Development – CEHD. University of Louisville	

Student Representative – NCATE	2002
CEHD accreditation process. Representing the Education Graduate Student Association	

Instructor Participant	2001 – 2002
Early Warning Program. Undergraduate Studies: Resources for Academic Achievement - REACH - University of Louisville	

President - Education Graduate Student Association	2001 - 2002
CEHD – University of Louisville	

Treasurer - Education Graduate Student Association	2000 - 2001
Louisville, KY. CEHD – University of Louisville	

Teaching and Learning Department Chair Search Committee	02/2001
Student Representative	
CEHD – University of Louisville	

Department Chair Five-Year Review Committee. Special Education	2000
Student Representative	
Department. CEHD – University of Louisville	

College of Education and Human Development Diversity Committee **1999 - 2001**
University of Louisville. Louisville

COMMUNITY SERVICE

Volunteer Interpreter/Coordinator – OK Mamas **2005**
Hispanic Parent Support Group in the Oklahoma City

Volunteer Translator – Down Syndrome Association of Oklahoma **2005**
Oklahoma City Association for families of children with Down Syndrome

Volunteer Translator - The Center for Women and Families **4/2001 – 6/2003**
Louisville, KY. Translated into Spanish children's stories for preventing domestic violence, reading materials for adult victims of abuse, and various legal forms

Volunteer Interpreter **2001, 2002**
Summer art therapy program for refugee children offered by Catholic Charities of Louisville. Interpretation was provided to Cuban children

Coordinator for Special Projects **1999-2001**
Hispanic/Latino Coalition of Louisville, KY

Volunteer Crisis Counselor. **1999**
Crisis and Information Center (CIC) - Seven Counties Services

PROFESSIONAL SERVICE

Manuscript Reviewer **2002 – Current**
TEACHING Exceptional Children - TEC

Editorial Board Member **2002 – 2003**
The Journal of International Special Needs Education

ACADEMIC AWARDS

Grawemeyer Fellow **2001-2003**
College of Education and Human Development, University of Louisville

Samuels Scholar **2000-2003**
College of Education and Human Development, University of Louisville

Delta Zeta Award in Special Education

2000

Outstanding scholarship, leadership, and service. Department of Special Education.
School of Education, University of Louisville

Faculty Favorite

2004

Delphi Center for Teaching and Learning – Student nominated award

PUBLIC SERVICE AWARD

Mary D. Rudd Volunteer Service Award

2002

Awarded by The Center for Women and Families. Louisville, KY